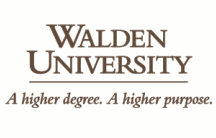

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The lived experience of HIV-positive Tanzanian orphans

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This is to certify that the doctoral dissertation by

Carol Parker

has been found to be complete and satisfactory in all respects,
and that any and all revisions required by
the review committee have been made.

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2009

ABSTRACT

The Lived Experience of HIV-Positive Tanzanian Orphans

by

Carol A. Parker

MPH, University of Illinois at Chicago, 1993
B.A., Ohio University, 1970

Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy
Public Health

Walden University
November, 2009

ABSTRACT

The purpose of this investigation was to generate a context- specific model of the lived experience of HIV positive Tanzanian orphans. With the advent of anti-retroviral drugs, Sub-Saharan African populations with high burdens of human immunodeficiency virus (HIV) face annually accumulating increases in the number of HIV positive children, and ultimately adults. Perinatally infected, these children often become orphans while still young. Extended interviews were performed with a purposive sample of 12 HIV infected orphaned children between 9 and12 years of age. Half of the research participants lived in an orphanage and half were children living with guardians in villages near Arusha, Tanzania. A phenomenological approach to data analysis was employed with the guidance of literature-based constructs of intrinsic traits and developed tools used by children to meet challenging life circumstances. Data demonstrated that disclosure of HIV and orphan status engendered widespread social consequence. The phenomenon also negatively affected the children's physical, material, and emotional quality of life. Even in the face of these challenges, participants demonstrated resilient and self-reliant coping mechanisms. Responses ranging from caretaker education to stigma reduction in the schools will help to meet the needs of these children. In addition, the information generated by this research will be a basis for beginning to examine the social change responses that will be necessary for Tanzanians in the healthcare, social service, and policymaking arenas to successfully integrate this new population group into all levels of society.

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DEDICATION

This work is dedicated to my parents, Beverly and Irwin Pochter, who always thought we needed a doctor in the family.

"It's never too late to become what you might have been." (George Eliot)

ACKNOWLEDGMENTS

Completion of this dissertation is the culmination of a life-long fascination with how we relate to health and illness. The opportunity to perform first hand research in the field is a dream that has been supported by many. First, thanks to Dr. Alvin Becker, the veterinarian who allowed me, as a 10th grader, to observe and assist on animal surgeries and begin to understand the wonders of the body. Professors and colleagues at the University of Illinois at Chicago provided the first real academic community for my public health inquiry. My Walden University Dissertation Committee, Drs. Morton Wagenfeld, Sigrin Newell, and Maria Rangel have been invaluable support, providing patient and enthusiastic guidance to this work. Research and professional partners in Tanzania have guided my growing understanding of the culture and intrinsic beauty of the Tanzanian people. Special thanks to Elizabeth Nguma and Steven Ndosi, my invaluable local research team. I want to thank my children, and the Tanzanian children, who have taught me much about the resilience of the human spirit, and the hopeful expectation with which we all arrive in this world. Finally, thank you to Craig Hale, who has said "yes" at every crossroad along this journey.

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CHAPTER 1:

INTRODUCTION TO THE STUDY

The effects of orphanhood, from grief to poverty, are pervasive facts of life in communities where AIDS has had a devastating effect. The 2006 World Health Report of the World Health Organization (WHO) estimated that by 2010, 12 million African children may be orphaned by AIDS (WHO, 2006). Much research has been conducted in affected African countries on the psycho-social and economic effects of orphanhood upon children since the advent of the AIDS epidemic. Research on the topic of children who are not only orphaned, but themselves infected with the human immunodeficiency virus, as well as discussions on the ground in Tanzania, revealed that those in the healthcare and social service arenas, as well as policymakers, have not begun to comprehend or prepare for this newest challenge to developing countries from the virus (Alvarez & Rathore, 2007). According to statistics compiled in 2006 by WHO and the United Nations Program on HIV/AIDS (UNAIDS), children currently represent 12% of all new HIV infections, more than 200,000 children living in Sub-Saharan Africa were newly infected with HIV in 2006 alone (UNAIDS, 2006). With the advent of antiretroviral drugs, Sub-Saharan African countries with high burdens of disease face annually accumulating increases in the number of infected children, and ultimately infected adults.

It was late 2005 before WHO published guidelines for the care and treatment of children with AIDS, even though it was acknowledged that infected children numbered in the millions in Africa alone (WHO, 2006). Although available to upper income countries

for some years, pediatric formulations of anti-retroviral drugs (ARV's) finally became available to the populations of resource-poor countries in 2005, increasing the need for well-defined protocols to support the physical health of children who now could look forward to adulthood (Alvarez & Rathore, 2007). Care and Treatment Clinics (CTC) in Tanzania are currently gearing up medication and clinical support to extend the physical lives of these children (Tanzanian Commission for HIV/AIDS, 2002). Because the treatment of pediatric HIV/AIDS has begun in Africa so recently, little data is available about the efficacy of the new protocols. What researchers have described, however, is a decline in mortality over time in those children who are receiving antiretroviral therapy (ART) (Bolton-Moore, et al, 2007; Domek, 2006; Puthanakit, et al., 2005). A distinct societal group has emerged with the potential to have great effect upon the economic, behavioral, and social aspects of Tanzanian, and all African, culture. This group has yet to be described, that is the AIDS orphan who is himself infected with HIV. This phenomenological study provides first steps in the description of the characteristics, perceptions and quality of life of members of this segment of Tanzanian society and will support its location within the greater whole.

Problem Statement

Low resource nations with a high burden of HIV are only recently becoming aware of a new societal group: orphaned children infected with AIDS without their own participation in risk-taking behaviors, but simply by having been born to infected mothers. Recent developments in the care and treatment of these children now means that they may look forward to growing to adulthood, and becoming part of the wider society

in which they live. Yet because of the very treatments which now support their physical lives, they face challenges that have yet to be described or understood.

The countries in which these children live are without the knowledge to recognize or meet the needs of this important new sector of their population. Shisana et al. (2006) point to the "growing need for applied social science research to provide scientific evidence for use in both policy and program development in the health sector to match the strides made in clinical medicine".(p. 230) According to Webb (2005), the five key strategies outlined in the UNICEF/UNAIDS Children on the Brink- 2004 report "provide a framework for highlighting some of the knowledge gaps and debates arising in discussions of the socioeconomic impacts of AIDS on children". (p. 22) The report called specifically for:

> 1. Increasing the ability of families to support and care for children impacted by AIDS by both prolonging parents' lives and developing responses to the financial, psychological, and other needs of these households.
>
> 2. Developing and supporting programs within communities that offer emergency as well as longer term support to households in need.
>
> 3. Helping orphans and other vulnerable children to be accorded their rights to, among other things, education and healthcare.
>
> 4. Working with governments to ensure the protection of AIDS impacted children through policy and legislative response as well as financial support to communities.
>
> 5. Increasing the level of awareness about the challenges and needs of children affected by HIV/AIDS in order to build collaborative responses.
>
> (UNICEF, 2004 pp. 22-23)

Item number 5 highlights the gap in the literature that this investigation addresses, and will thereby provide guidance for the strategic responses outlined above. By describing the lived experience of HIV positive Tanzanian orphans, this research supports a public health, community- based approach to both policy development and strategies to meet the needs of HIV positive Tanzanian children as well as facilitate their integration into the wider society.

Background of the Problem

When the first African cases of AIDS were identified in 1983, few could predict the economic and social consequences of the worldwide pandemic of the human immunodeficiency virus (WHO, 2006). The greatest burden has been borne over time by the countries of Sub-Saharan Africa, which carry 64% of the worldwide prevalence of HIV infection (UNAIDS, 2007). Millions between the ages of 15 and 45 have died, decimating the generation of economically generative persons (UNAIDS, 2006). Newly developing nations on this continent began to lose many of the gains in productivity and worldwide economic engagement hard won prior to the 1990's (UNAIDS, 2006). In addition to the loss of millions of productive lives, the continent lost a generation of parents. An estimated 12 million Sub-Saharan African children have been left as AIDS orphans between 1990 and 2005 (UNAIDS, 2006).

In 2004, scale up of the distribution of low cost antiretroviral drugs and advances in understanding, treating and preventing opportunistic infections and other AIDS related comorbidities began to offer an alternative to the implicit death sentence of HIV infection in resource-poor countries (UNAIDS & WHO, 2006). Although progress was

slow, utilization of the drugs and other treatments by infected persons began to offer guarded optimism about stemming the tide of loss in sectors as diverse as government, education, business, and agriculture. An increasing number of adults were living longer and providing economic support and care to the next generation. (UNAIDS & UNICEF, 2004).

Concurrently, the health care establishment became aware of the consequences of the spread of HIV by mother-to-child transmission. A majority of mothers giving birth in Sub-Saharan Africa had not been tested for HIV during pregnancy or, if tested, were unwilling to reveal the outcome. (Alvarez & Rathore, 2007) This meant that many HIV positive mothers were unsuspectingly infecting their infants. Over time, successful treatment modalities for minimization of the risk of maternal child transmission were developed, but in most countries were only offered to those mothers who knew, or wished to know, their own status (Etiebet, Fransman, Forsyth, Coetzee, & Hussey, 2004). In 2006, approximately 6% of pregnant African women were offered treatment to prevent maternal child HIV transmission (Ammann & Burrowes, 2007). Without intervention, approximately 35 % of children born to HIV- infected mothers are themselves infected (Etiebet, et al., 2004). In 2006, UNAIDS estimated the pediatric HIV burden in Sub-Saharan Africa at 2.3 million children under 15 years (UNAIDS, 2007). Many of the mothers who perinatally transmit the virus to their infants ultimately die, leaving care of HIV- infected children to their families or the wider society.

Prior to the development and distribution of pediatric antiretroviral formulations to sub-Saharan Africa, over 50% of children born infected by HIV died within their first

2 years, and most in their first decade (Brahmbhatt et al., 2006). As ARV's and treatment for opportunistic infections became available to children, African countries became aware of the large numbers of children who were infected, might utilize the therapies, and thereby live into adulthood.

In 2005, Tanzania, among other countries, began to earmark 10% of the supply of ARV's for pediatric use (UNICEF, 2005). In 2006, WHO published its first guidelines for the use of antiretroviral therapy in the care of infants and children infected with HIV. This watershed event marked the beginning of hope for the millions of infected children living in resource-poor settings (WHO, 2006).

AIDS in Tanzania

The first African cases of HIV were confirmed in 1983 on the northwest border of Tanzania with Uganda, along the coast of Lake Victoria (Tanzanian Commission for HIV/AIDS, 2002). This area is a heavily trafficked trade juncture among African countries as well as to the rest of the world. Spread of this as yet barely known virus was rapid, and without significant immediate effect upon those carrying and spreading it (Tanzanian Commission for HIV/AIDS (TACAIDS), 2002). Because of the location of the early cases, HIV spread into the general Tanzanian population before the magnitude of the problem was revealed in other areas of the world, or public health and other entities could begin to comprehend or respond to the emergency. In 1986, the government of Tanzania developed its first National AIDS Control Programme (NACP). Despite this fledgling effort, Tanzania experienced a doubling of prevalence rates of HIV infection between 1990 and 2000, when the rates were estimated at between 13 and 20 %

of the total population (Tanzanian Commission for HIV/AIDS (TACAIDS), 2002). Based upon this finding, a series of wide-ranging national initiatives to prevent the spread of HIV were begun, culminating in the National Multi-Sectoral Strategic Framework (NMSF) on HIV/AIDS for the period 2003-2007. The goals of NMSF were in line with international agreements and commitments for provision of low cost anti-retroviral drugs. In addition, they conformed to the Millennium Development Goals and the recommendations of the United Nations General Assembly Special Session on HIV/AIDS (UNGASS) of June, 2001 regarding scale up of medical facilities to deal with infected persons, in addition to increased availability of HIV education, counseling and testing.

The most recent estimates of HIV/AIDS prevalence in Tanzania are based upon 2005 data collection and models. According to UNAIDS/WHO (2006), approximately 1.4 million Tanzanian persons above 18 years are living with HIV/AIDS, and an estimated 210,000 children under 14 years are similarly infected (UNAIDS, 2006). National seroprevalence, or the rate of laboratory confirmed HIV positive persons in a population, varies at between 7- 20% depending upon locale and population density (UNAIDS, 2006). It is widely believed among healthcare and social service providers that, because much of the population either lives in rural areas or does not participate in organized healthcare delivery systems, the actual number of Tanzanians infected with HIV has been grossly underestimated.

The most important statistic to this study is the continued high rate of infected women giving birth to children who may be infected. Data collected in 2003-2004 at

prenatal clinics in 10 Tanzanian geographical regions revealed an average HIV prevalence rate of about 10% among pregnant women (Swai, et al., 2006). Recent initiatives to offer HIV counseling and testing to mothers arriving for prenatal care or imminent delivery may help to reduce this rate. However, with only 46% of Tanzanian mothers utilizing a skilled birth attendant, the ability of the health care system to provide prevention opportunities for maternal-child HIV transmission are severely limited (UNAIDS, 2006). In an environment where one can expect to see an undiminished incidence of HIV- infected children for the foreseeable future, and the specter of the death of many of their parents before these children reach adulthood, the societal impact of HIV- infected children continues to loom large.

The Context

Tanzania is the largest country in East Africa, at nearly 365,000 square miles. With the Indian Ocean to the east, Tanzania shares borders with Kenya, Uganda, Burundi, Rwanda, Democratic Republic of the Congo, Mozambique, Zambia, and Malawi. Lake Victoria, the largest inland body of water on the African continent, is located on the northwest border, and provides a transportation hub between many countries as well as hydro-electric power to much of Tanzania (United Republic of Tanzania, Office of the Prime Minister, 2002). Although agriculture employs nearly 80% of the population and provides the largest number of exported products, only about 4% of the land is useful for agricultural production due to topographic limitations including poor access to water (United Nations Development Program (UNDP), 2006).

In 2006, the population of Tanzania was estimated at approximately 38 million people (UNDP, 2006). Density in the country is uneven, with 80% of the population living in rural areas. Importantly, nearly 50% of the population is less than 20 years old (UNICEF, 2006).

Arusha Region

Tanzania is divided into 26 administrative regions. The capital of the Arusha Region is the city of Arusha. Many of the significant game parks, including Ngorongoro Crater and the Serengeti are located in the region, making Arusha the base for the safari circuit. According to the 2002 Tanzanian National Census, the population of the Arusha Region was 1.3 million persons. After Dar es Salaam, the city of Arusha is the most significant commercial center in Tanzania. However, since less than 50% of the population has education beyond the primary level, employment rates remain low (UNDP, 2006).Most residents of Arusha Region who do not live or work in the city are engaged in subsistence agriculture or the informal sector.

The Arusha and Arumeru Districts

The Arusha and Arumeru Districts are two contiguous geographic and administrative areas in the northeast sector of the Arusha Region that utilize the same set of health and other services. For the purposes of this investigation, description of the residents of the districts is limited to those who do not live in the municipal area. Transport through these rural areas is provided by a single 2 lane highway in addition to a network of narrow, mostly unpaved, roads leading to and from the villages and sub-villages that extend up into the hilly and densely planted areas on either side.

Most of the residents of the Arusha and Arumeru districts live on ancestral parcels of land in small houses made of mud or bricks with roofs of tin. It is common for many persons of several generations to live together or very near to one another, as the bonds of tribe and family still create community. However, in recent years, economic conditions have forced many adult children to leave their home villages in pursuit of higher wages in the cities or the mines (UNDP, 2006). This often leaves elders to care for themselves or rely on the charity of neighbors. The average per capita income in Tanzania is 770 USD (World Bank, 2006), and in 2006 the United Nations Development Program put the United Republic of Tanzania at number 159 of the 177 ranked nations.

The Children of the Arusha and Arumeru Districts

The life of a child in Tanzania is dictated by the economic situation of his parents or guardian. In families where one or both parents are wage earners, a child can expect to have their basic nutritional needs met, and to attend at least primary school. Government primary schools do not charge tuition, but the student must wear a uniform and families are responsible for providing school supplies, food and transportation. There are no free secondary schools. Attendance at the lower-cost government secondary schools is based upon primary school performance and examination, and only 10% of students qualify. All other children wishing to attend secondary school are faced with raising money for school fees that may constitute more than half of a family's yearly income. Secondary school attendance is a luxury few families can provide to their children.

Health and health care of children living in Tanzania is variable. The infant mortality rate is estimated at 76 per thousand and malaria remains the number one killer

of children under 5 years of age (UNICEF, 2006). Free clinics for children are available at government hospitals, but the family must usually pay for medication when it is needed. This means that although basic treatment and childhood vaccinations may be available to all, medication to treat the endemic typhoid fever and malaria, or diarrhea contracted through unsafe water and food sources, is beyond the means of many families.

Nutrition is dependent upon the economic situation of the family. The standard diet consists of ugali, a cornmeal mush, and rice complemented with vegetables and fruits, accompanied by milk tea. Protein is not available daily in most households. The majority of homes do not have running water or electricity, or thereby, refrigeration (United Republic of Tanzanian, Office of the Prime Minister, 2002).

Children are expected to be fully functioning members of the family. They collect firewood and water, care for younger children and livestock, and assist in the income generation activities. Corporal punishment is an expected part of training children in proper behavior, but excessive beating or use of force against children can engender intervention by other family members, neighbors, or village leaders. No formal governmental social or psychological services are available to adults or children in the Arusha Region. This role is inadequately filled by locally trained natives and volunteers working through non-governmental organizations that are funded by the international donor community.

Orphans. Orphaned children in the Arusha Region usually live with extended family or elderly grandparents, in sibling groups, or with informal guardians. Some of these homes provide loving and supportive environments, while others look upon the

orphans in their care as unwelcomed burdens that negatively impact the lives of others in the home (Cluver & Gardner, 2007). Orphans may fully enjoy the quality of life of the rest of the family, or may be denied adequate food or school fees (Cluver & Gardner, 2007). Some children report harsh treatment or excessive work burdens (Cluver & Gardner, 2007; UNAIDS, UNICEF, WHO, 2007). Orphanages have proliferated in the region since the advent of the AIDS epidemic, and are full to overflowing with children who are without extended family or whose families simply cannot fill another mouth. There is no governmental or public funding mechanism to support the needs of children in orphanages. The current Tanzanian government policy regarding orphans advocates a return to village support of orphans rather than residential placement and the concomitant dislocation of so many children (PEPFAR, 2008).

Care and Treatment of Persons with HIV/AIDS in the Arusha and Arumeru Districts

Several public and private hospitals are located in Arusha municipality, in addition to the Arumeru District Hospital in Patandi Village, and Nkoanrua Hospital in the village of the same name. Kilimanjaro Christian Medical Centre, located in Moshi some 70 kilometers to the east, is the regional referral hospital serving residents of the entire region. The Tanzanian government has supported development of a network of Care and Treatment Clinics for persons suffering from HIV/AIDS at all of these institutions (Tanzanian Commission for HIV/AIDS, 2002). Clinics are not differentiated as adult or pediatric. Once a person meets the required clinical qualifications for care, a record is created and the patient is issued a blue card that identifies them, provides

information regarding the drug regime they are following, and also an appointment schedule.

Most patients visit the clinic once each month for follow up and medication distribution. Anti-retroviral medication is distributed without charge under agreements between the Tanzanian government, the donor community, and drug manufacturers. (UNAIDS, 2006).However, medications necessary for the treatment of the common opportunistic infections associated with HIV/AIDS are the financial responsibility of the patient. In addition, the cost of transport to the clinic is often an insurmountable financial obstacle and leads to lack of medication compliance among the HIV/AIDS infected population (Hardon, et al, 2007). In some areas, networks of community health workers (CHWs) have been created by non-governmental organizations that provide psycho-social support as well as limited pain medication, vitamins, or food supplementation to patients. It is often the secondary infections or financial implications of the disease that ultimately are the cause of death for Tanzanians with AIDS.

Nature of the Study

Husserl (1859-1938) is considered the father of the philosophical approach to understanding human experience called phenomenology. Husserl called phenomenology the science of descriptive psychology (Husserl, 1931). Following his introduction of the concept, other continental philosophers, including Heidegger and Merleau-Ponty, explored and expanded upon the themes, and soon after phenomenology became widely utilized in social science inquiry (Spielberg, 1982). Stewart and Mickunas (1990) described the basic tenets of phenomenological research. First is the Husserlian concept

of epoche, which emphasizes the collection of information without pre-judgment (Stewart & Mickunas, 1990). This method of inquiry utilizes the medium of the spoken word to share informant data with the researcher (Stewart & Mickunas, 1990). There is no attempt to divest the narrative of distortive thinking, which might be done in empirical research, as the words are the verbally described true experience of the subject in relation to various aspects of the phenomenon under consideration (Stewart & Mickunas, 1990). The second tenet of phenomenology regards the inseparable connection between an object or phenomenon, and the individual's consciousness of it. Husserl called these two aspects of a single idea the *noema*, or object of a perception, and the *noesis*, that person's internal response to it. By viewing the interaction as a whole rather than a sum of its parts, the researcher is able to describe the meaning of an entire experience as a unified individual perception.

This study utilized the phenomenological approach with individual Tanzanian orphaned children experiencing HIV positive status. Extensive interviews provided in-depth information about their lived experience, and analysis of the individually derived data elucidated the central themes that contributed to description of the universal meanings implicit in the phenomenon as experienced by this set of subjects. Creswell (1998) called this the psychological approach, which derives from the Duquesne Studies in Phenomenology (Moustakas, 1994). Because an inductive approach to the transcribed interviews was taken, the research ran true to the tenets of phenomenological investigation, and meaning was elucidated from experience. This became, then, a

descriptive, rather than proscriptive, investigation. Theoretical underpinnings and methods for data collection and analysis will be further described in Chapter 3.

Research Question

What are the qualities of the physical, emotional, intellectual and social experience of living as an HIV-infected Tanzanian orphan?

Subquestions

1. How do HIV-infected Tanzanian orphans think they compare to other children (a) physically, (b) emotionally, (c) intellectually, and (d) socially?
2. How do HIV-infected Tanzanian orphans perceive what the society is telling them about their identification as orphans infected with HIV?
3. What factors are present that support these children in coping with both orphanhood and positive HIV status?
4. How do these children rate on standardized quality of life indicators?
5. How do HIV-infected Tanzanian orphans living in institutional settings compare on the above four parameters to similarly-described children living in village settings?

Purpose of the Study

The purpose of this study was to describe and explore the beliefs, perceptions, responses to and meanings embedded in the lived experience of HIV-positive orphaned children living in the Arusha Region, Tanzania. An important aspect of the study was elucidation of the presence or absence of intrinsic attributes or coping skills that may

enable the children to successfully function subject to the conditions of their lives and within their society.

The first step to responding to a phenomenon is secured through description of it. At present, the literature does not provide either description of, or the basis upon which to understand, HIV- positive orphanhood. This study documented how these children see their own lives, how they see themselves in relation to their peers and community, and what meaning they ascribe to these interactions. In this way, the findings will support those who will be working to meet the needs of these children as well as facilitate the integration of this as yet undescribed group into the wider society of resource-poor countries with high burdens of HIV disease. Comparison of the experience from children living in institutional placements and those living with extended family or guardians in the villages provided additional information to be utilized in future program planning and resource allocation decisions.

Conceptual Framework

In order to describe the phenomenon of HIV positive orphan hood, I utilized a framework that I formulated by modifying well documented mechanisms to fit the context of rural Tanzania. The resulting description of the phenomenon as experienced encompassed the realms of the physical, intellectual, emotional, and social self of the children. The attributes of the experience of HIV positive orphanhood were particularly identified by using several interrelated concepts of the personal characteristics and developed skills that support children's healthy functioning when faced with challenging life circumstances. This framework utilized elements of the locus of control, resilience,

learned resourcefulness, and chronic disease models to identify the ways in which these children experience their lives. Figure 1, below, describes the framework of interaction between life conditions and coping mechanisms that will be identified and described in Chapter 4.

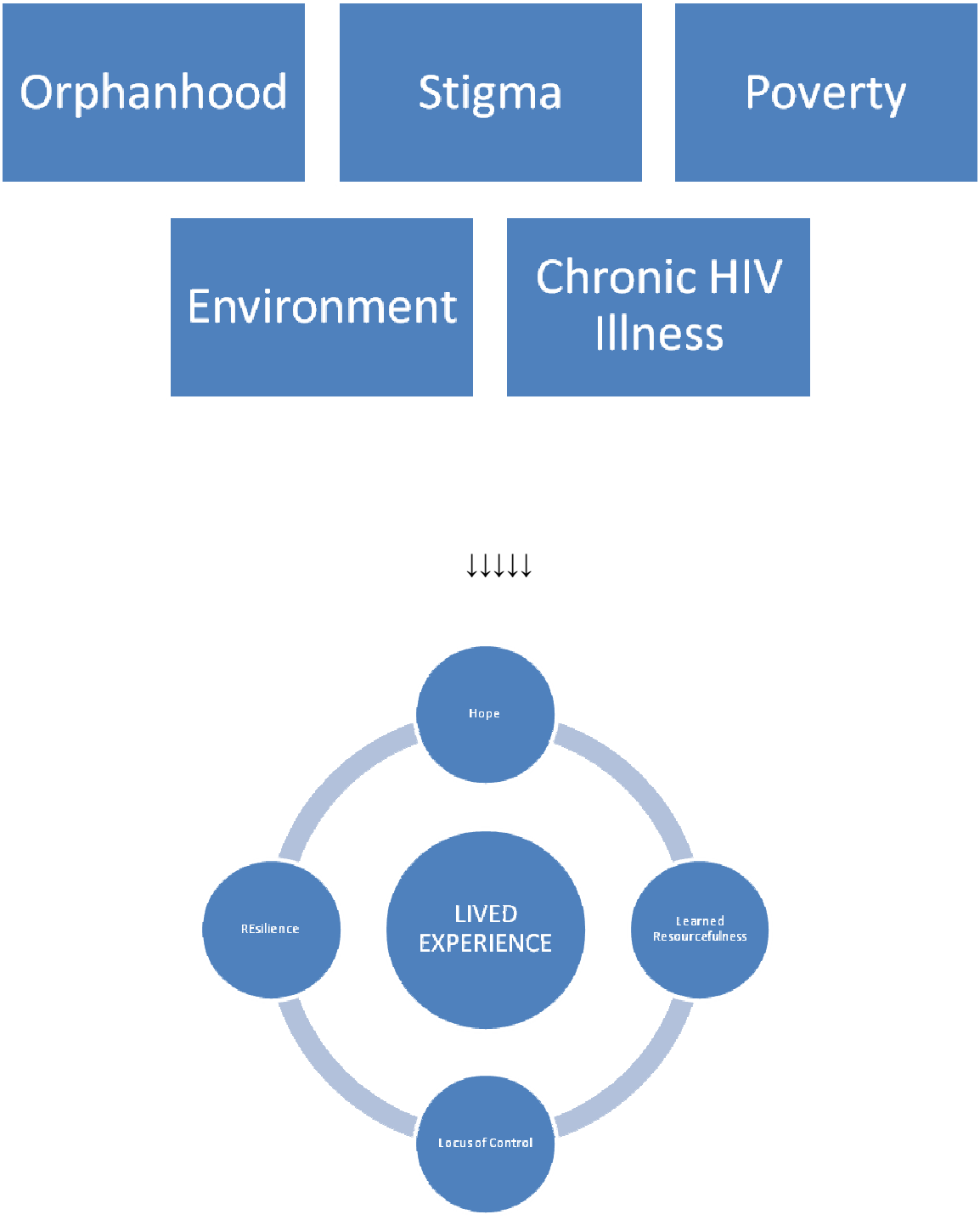

Figure 1. The Lived Experience of HIV Positive Tanzanian Orphans

Operational Definitions

AIDS: Acronym for acquired immune deficiency syndrome, the advanced stages of disease engendered by infection with the human immunodeficiency virus. Clinical confirmation of progression to full-blown AIDS consists of laboratory confirmation of HIV viral load, the presence of secondary (opportunistic) infections or malignancies, and reduction in CD-4 lymphocytes to less than 350 per cubic millimeter of blood (WHO, 2006).

ARV's: The acronym for antiretroviral medication. This class of pharmaceuticals either reduces the rate of replication of the HIV virus or supports the production of the body's T-cells, which fight against the effects of the virus upon the host. Treatment with these agents is often called antiretroviral therapy, or ART. In developed countries, over 30 medications are available to be used in various combinations to address the unique needs of a patient as their disease progresses. In sub-Saharan Africa, one of two standard single dose combinations is the normative treatment (WHO, 2006).

Bracketing: In phenomenology, the researcher must ignore personal judgments, conditioning, and beliefs in order to learn about an experience as it is lived by the person who is describing it. Thus, the researcher *brackets* their own set of beliefs and experiences in order to perform a pure descriptive function (Husserl, 1931).

HIV: Acronym for human immunodeficiency virus. This virus is responsible for the development of AIDS. Initial infection presents with flu-like symptoms such as rash, low grade fever, or swollen lymph nodes. Development into serious symptoms and AIDS may take many years and often is untraceable to the source of initial infection (WHO, 2006).

Institutional placement: For the purposes of this study, an institutional placement means an orphanage where caretakers are not relatives or informal guardians (Shisana et al., 2006).

Orphan: In African culture, a child who has lost one or both of their parents to death. Because the impact upon a child of the death of even one parent in a resource-poor setting can result in increased psychological burden, decreased economic circumstances, and the possibility that the child will be left to care for a sick remaining parent, loss of one parent is considered as having at least as much effect upon the life of the child as the loss of both parents. Children are called, therefore, single orphans or double orphans (Shisana et al., 2006).

Resilience- The constellation of characteristics that create the "process of, capacity for, or outcome of successful adaptation despite challenging or threatening circumstances" (Masten, Best, & Garmezy (1990) as cited in Howard, Dryden, & Johnson, 1999).

Resource-poor countries: Resource-poor countries are defined by the United Nations as those significantly lacking in infrastructure needs as diverse as schools, social support, access to medical care, roads, power sources, or communication availability.

Nations are ranked based upon both these parameters and the financial and developmental ability of the government to meet the needs. Tanzania is ranked at 159 out of 177 nations

(UNDP, 2007).

Seroprevalence: This term is used to describe the prevalence of persons within a population who have antibodies to a specific disease as confirmed by analysis of blood serum (Little, Newell, et al., 2007**).**

Stigma: In the context of HIV research, stigma is the negative response of individuals and societies to the awareness of a person's infection with HIV. This response may encompass discriminatory behaviors along a spectrum from avoidance of the person or gossip, to activities designed to chase the person from their home or community (Hamra & D'Agostino, 2006).

Vertical infection: The human immunodeficiency virus (HIV) can be passed from a mother to her child perinatally, at the time of birth or during breastfeeding. Testing for the presence of the virus before birth can provide the information necessary to administer medication that significantly reduces the possibility of passing the infection to the child (Etiebet et al., 2004).

Assumptions

1. Discussions and interviews regarding the sensitive topic of HIV/AIDS are often difficult and emotionally charged.

2. Cultural norms and environmental circumstances affect the perceptions and responses of those experiencing a phenomenon.

3. The attitudes and perceptions of children are rarely solicited or considered important in Tanzanian culture. This means that the children may be unaccustomed to speaking freely about their experiences.

4. Tanzanian children who have revealed or are aware of their HIV status may have experienced some stigmatizing or discriminatory behaviors.

5. Access to and utilization of medical and/or psychological care for these children has been uneven.

Limitations

1. The researcher is not a native Swahili speaker, so confirmation of language congruence is not assumed.

2. A purposive sample of children constitutes the study group. This study, because of the small sample size, looked at selected but not all, aspects of the phenomenon. No generalization was attempted from the findings.

3. The goal of this study was to provide a preliminary description of a defined group of children experiencing the phenomenon of HIV positive orphanhood.

4. Data was self-report from children. It is, therefore, deemed reliable only in that they were derived in the first person.

5. Although every attempt was made to remove personal or professional bias from data analysis, this researcher acknowledges that she derives from a different culture and race than the respondents. In addition, the author acknowledges ongoing

relationships with the organizations and personnel who will be community resources for the identification of participants.

6. Interviews were conducted by a trained local research assistant rather than the head Researcher, which may have led to inconsistent data collection.

7. Because many of the families in rural Tanzania are poor, it will not be possible to determine if poverty-related poor quality of life is directly attributable to HIV positive orphanhood.

8. Consistent medication adherence or self-care by HIV positive orphans has not been attributed to learned behavior or other type of response to life with a chronic disease.

9. Resilience in the face of HIV positive orphanhood may be either culturally linked, a cognitive response to the stresses of the phenomenon, or both.

10. Because adult interviewers solicited responses from children, perceived power inequity may have influenced the responses.

The possibility of limitations regarding language were be mitigated by (a) performing the interviews in the native Swahili language, (b) securing professional translation of the transcripts from Swahili into English and back translating to secure congruence utilizing bilingually proficient persons, and (c) re-interviewing as necessary in Swahili for further exploration of word or phrase usage that seemed in need of clarification. The possibility of limitations regarding bias of the head researcher was mitigated by the use of a trained local research assistant to collect the data. The possibility of limitations regarding the data collection by a local research assistant rather

than the head researcher was mitigated by her advanced level of education, experience with children, and length of time in the field. This person was well trained in order to reinforce the importance of self report by children as well as to teach her how to minimize power disparities between adults and children. Other limitations derived from the data analysis in areas where no determination of causation or linkage could be made.

Delimitations

This study was delimited in several ways. The definition of phenomenology limits the information gathered to that which supports the analytical approach. This extends to decisions regarding the parameters of the methodology inherent in the research design. Specifically, the use of first person description delimited the data to that which was reported by the subjects rather than secondary report or observation. In addition, this study examined data on descriptors chosen by the researcher, and is in no way to be construed as the full range of parameters that might be used to describe the experience of HIV positive orphanhood.

Social Change Significance of the Study

This study described and began the process of defining the characteristics of an emergent group in Tanzanian society: HIV-positive orphaned children. The primary purpose of this investigation was to support the social integration of HIV infected orphaned Tanzanian children, while providing first steps to minimize the psychology of blame directly associated with HIV status that is endemic in less developed societies. Because the needs and impact of the large numbers of children who fit the criteria have not yet been addressed, this study began the necessary dialogue to engender further

research that highlights and promotes the necessary social change responses of Tanzanian, and all African, society.

In many countries of Africa societies have been caught completely unaware of the future impact of a large segment of young people who are HIV infected from birth and orphaned, but who are capable of becoming productive citizens through the use of antiretroviral therapy (ART) and other interventions. Social change will be necessary in response to this phenomenon on every level, and in every setting. Changes in everything from workplace rules and access to education, to the transmutation of long-held beliefs about the meaning of HIV infection, will occur (Domek, 2006). This research contributes to the development of progressive social change responses.

Summary

As access to antiretroviral drugs and other treatments to fight AIDS improves in resource-poor nations, an increasing number of African children are living with HIV as a chronic, rather than fatal, disease. Many of the infected children are also orphans. Because these are recent developments, the lived experience of HIV positive orphans has not yet been described. Phenomenological description of this emergent group is necessary to promote integration of the children into their society, and for the society to be responsive at all levels and in all institutions to these blameless victims. HIV positive children living in the Arusha Region of Tanzania provided the sample for this study. Chapter 2 will review the literature on areas of inquiry attendant to the investigation and describe research gaps that remain to be filled. Chapter 3 will provide the methods that

were utilized to generate data for the analysis in chapter 4 and the recommendations of chapter 5.

CHAPTER 2:

LITERATURE REVIEW

Introduction

Chapter 2 describes the research and theories found in publications related to AIDS orphanhood and pediatric HIV/AIDS infection, including mode of transmission, and the ways in which children exhibit or develop coping mechanisms when faced with chronic illness and/or orphanhood. This literature review concentrated on data generated and theories tested in Africa and other less-developed parts of the world in order to recognize their usefulness in the setting of this research. Some additional work that has been performed in the United States and Europe has also been included when such literature contributes to understanding of the issues at hand. The limitations of previous studies, as well as the adequacy of theoretical constructs and the instruments that have been developed to support them, are explored. In addition, the literature review describes the paucity of, and the need for, research to describe the lived experience of Tanzanian children who are both orphans and infected with HIV/AIDS.

Literature Search

The literature reviewed covered the period 1995-2008, but includes older theories and instruments designed to support the theoretical constructs. Databases utilized in this literature search included Academic Search Premier, Ovid Medline, PsycARTICLES, PsycBOOKS, SocINDEX, Proquest Dissertation and Theses, Cochrane Reviews, and CRISP. Search terms used individually and in all useful combinations included *HIV, AIDS, pediatric, orphanhood, antiretroviral therapy, Africa, chronic disease, resilience,*

stigma, locus of control, learned resourcefulness, sense of coherence, phenomenology, and *vertical transmission.* A total of 4,426 articles, book chapters, books, and conference presentations were identified that met the search criteria. Two hundred sixty eight were utilized in the review and elsewhere in this study.

Pediatric HIV/AIDS in the Developing World

Nearly 25 years have passed since the first pediatric AIDS cases were reported. During that period, the pandemic has escalated to the point where nearly 3 million children are reported to be living with AIDS worldwide, most of them in Sub-Saharan Africa (Domek, 2006). In addition, Alvarez and Rathore (2007) reported that children accounted for 12% of new infections reported in low income countries in 2006, indicating that the number of children living with chronic HIV/AIDS continues to increase. HIV infection in young children is tied to problems with growth, neurocognitive and motor development, and a host of other factors that impede full functionality (Alvarez & Rathore, 2007). Because many of these children are diagnosed early in life, those who are lucky enough to receive anti-retroviral drugs face the risks of drug resistance linked to long term use or inadequate medication adherence (Alvarez & Rathore, 2007). Yet in 2007, UNICEF reported that only 6% of the African children who were in need of anti-retroviral drugs were receiving them. In addition to the physical effects of HIV/ AIDS, infected African children face many psychological and social challenges, from the impact of parental death and concomitant economic insecurity to the grief and fear that derive from infection with a life-threatening and highly stigmatized disease (Domek, 2006).

Many gaps exist in both research on and treatment of HIV-infected children living in the developing world (UNICEF, 2007).

Vertical Transmission of HIV/AIDS to Children

Most of the African children who become infected with the HIV virus acquire it perinatally from their HIV infected mothers or through breastfeeding (Thorsen, Sundby, & Martinson, 2008). In the industrialized countries of the world, maternal-child transmission of the HIV virus is currently estimated at less than 2% while in less developed countries the rate is between 25-40% (UNAIDS, 2006). This is due in part to the widely differential availability of interventions or prevention programs geared toward HIV infected pregnant women (Pendergast, et al., 2007). Amman and Burrowes (2007) cited the UNAIDS statistic that 600,000 infants, 90% of whom live in Sub-Saharan Africa, became infected in 2006. Utilizing data on 17,813 women collected from 57 clinics in 10 geographical regions of Tanzania, Swai et al. (2006) found an HIV infection prevalence of 8.7% among pregnant women, which is higher than the national rate of 7%, and predicts a steady rise in new cases among children. Without any intervention, the rate of transmission from an HIV positive mother to her neonate is estimated at 35% (Crampin, et al., 2003). It is difficult to estimate how many children are perinatally HIV exposed in resource limited settings. Little et al., (2007) and others utilized perinatal and other data on trends in the morbidity and mortality of children under 5 years of age to create models of HIV infection rates in young children living in these countries.

Perinatal HIV Status

The literature includes discussion of efforts to reduce perinatal HIV transmission in Africa. The first factor considered in this complicated subject is the willingness of pregnant women to learn or reveal their own HIV status. The Centers for Disease Control and the World Health Organization support the strategy of offering HIV testing to all women attending prenatal clinics or arriving at hospitals close to the time of birth, with an option to refuse, or opt out, instead of asking them to opt in (Alvarez & Rathore, 2007). In 2005, however, the United Nations Regional Information Networks decried the poor counseling, when it was even available, for expectant mothers so that they might make informed choices about HIV testing prior to the birth of their child (UNAIDS, UNICEF, & WHO, 2007). In one study in South Africa, 6929 women were surveyed about their prenatal counseling experience (Etiebet, et al., 2004). Based upon responses, these authors made the assumption that widespread implementation of voluntary counseling and testing is slowed by the lack of acceptability of the process, as well as the social ramifications to a mother of knowing her own HIV status (Etiebet, et al., 2004).

Thorsen, Sundby, and Martinson (2008) explored the potential for increased marginalization of women who agree to be tested or perinatally treated for HIV due to the high levels of stigma toward the disease in Sub Saharan Africa. Clark (2006), however, evaluated these problems by cost/benefit analysis, and concluded that HIV testing of all women, combined with a full range of interventions designed to support the dyad, would save not only lives but increase the disability- adjusted productivity of infected mothers and children living in resource-poor countries.

Strategies for Reduction of the Rate of Perinatal Transmission

Although only an estimated 10% of expectant HIV positive African mothers are offered such support, there have been good results in diminishing the rate of HIV transmission to infants when appropriate prophylaxis interventions are implemented (Amman & Burrowes, 2007). Little et al. (2007) supported the effectiveness in resource-limited settings of Preventing Mother To Child Transmission (PMTCT) protocols. The tools utilized include HIV testing and counseling for expectant mothers, administration of one or more anti-retroviral agents at varying times during and after pregnancy, and counseling about appropriate infant feeding practices (Little, Thorne, et al., 2007).

Without any intervention, the maternal-child HIV transmission rate is estimated at 35% (Crampin, et al., 2003) with a median child survival for infected infants of 23 months (Brahmbhatt, et al., 2006). In one randomized controlled study conducted in Botswana, 1200 mothers and infants were treated with nevirapine or zidovudine and engaged in either exclusive breastfeeding or formula feeding (Thior, et al., 2006). At 18 months of age, the rate of HIV infection among the children ranged between 13.9-15.1%, depending upon which protocol the mothers followed (Thior, et al., 2006). This is an infection rate reduction of over 60%. However, the variability of programs, drug administration protocols, infant feeding support, and other kinds of interventions make measurement of effectiveness difficult, if not impossible, in resource-limited environments (Stringer, et al., 2008). Little et al. (2007) wrote “PMTCT and pediatric

ART have been shown to be highly successful in resource limited settings, but are not universally applied" (p. 139**)**.

HIV infected mothers must carefully weigh infant feeding decisions to minimize the risk of passing HIV to their infants. Although breastfeeding is the culturally accepted, and safest, form of infant feeding in Africa, it is estimated that 40% of the cases of HIV transmission from mother to child occurs during breastfeeding (Coutsoudis, Dabis, & Fawzi, 2004). At present, exclusive breastfeeding for less than 6 months followed by complete weaning, or exclusive formula feeding until other foods can be introduced, are the WHO recommended feeding practices for infants with HIV infected mothers (WHO, 2006).

Although formula feeding would seem to be a good choice to avoid transmission risk, it is often an unsafe practice for infants living in low-resource countries. This idea is supported by the fact that only 3% of the women in a large South African study had the clean water, adequate fuel, access to refrigeration, and regular maternal income which were viewed by the researchers as necessary to support replacement feeding that would not pose great health risks to the infant (Bland, et al, 2007). In the developing world, the risk to infants of infectious disease or malnutrition from unsafe replacement feeding is greater than the risk of HIV infection incurred with exclusive breastfeeding by women of low socio-economic status (Taha, et al., 2006).

Mothers who have recently learned their HIV status need support as they negotiate both the meaning of the diagnosis in their own lives and their current or future medical needs. In addition, the children who have been treated with ARV's or other

medication require monitoring and ongoing access to medication (Thior, et al., 2006). However, maternal- child follow up in countries with low socioeconomic populations can be problematic. Besides the actual cost of transport to the clinic and time lost from income generating activities, many mothers will avoid the reminder of their own, and their child's, mortality. In a Johannesburg, South Africa study of 176 women with HIV exposed infants, only 51% returned 2 weeks postpartum, and a meager 18% returned at the 12 month marker, when confirmatory HIV testing of the child would have been performed (Jones, Sherman, & Varga, 2005). Chuma, Gilson, and Molyneux (2007) investigated these factors in coastal Kenya, and discovered that these burdens, in addition to user fees for many clinic services and medications, place insurmountable stress upon poor mothers. Losing an HIV-infected infant to follow up means that the child may not obtain medical care again until they have suffered multiple infections and are already extremely ill. At that point, some long term effects on growth and overall health will have occurred, and extraordinary efforts must be utilized to treat the opportunistic infections and stabilize the immune system to prevent an early death (Little, et al, 2007).

Diagnosis and Physical Manifestations of Pediatric HIV/AIDS

Often the first clue to HIV infection in an African child is repeated bouts of an HIV defining illness such as herpes zoster, pneumocystis carini pneumonia, or oral candidiasis. An investigation performed by the Tanzanian Ministry of Health in 2004 found that these physical manifestations, as well as delayed development or recurrent diarrhea, often were the presenting problem that led to eventual HIV diagnosis (Somi, et al., 2006). Children who are not identified at birth as perinatally exposed often run the

risk of much later confirmation of their infection, and often at a later stage in the disease. In a study of 32 children 8-19 years old in Zimbabwe, the median age at first HIV test was 11 years, and averaged 3.5 years after the first HIV related infection (Ferrand, et al., 2007). These children presented with stage 3 or 4 CD-4 measurement (Ferrand, et al, 2007). They suffered from stunting of limbs and recurrent opportunistic infections.

The late 2005 inclusion of the first guide to HIV/AIDS diagnosis and treatment of children living in resource limited settings into The WHO Guide to Management of Childhood Illnesses was a watershed event that led credence to the importance of treating HIV positive children. This document described disease staging and provided a flow chart useful for treatment based upon presenting facts of the case that utilized widely available laboratory and medication options, rather than those that might be appropriate to high resource countries. The recommendations were evaluated in South Africa, and subsequently validated and revised in Ethiopia and Uganda, where the local economic situations and health care access are different (Qazi & Muhe, 2006). The WHO Pediatric HIV Clinical Staging chart appears as Table 1.

Table 1.

WHO Pediatric HIV Clinical Staging

	Clinical Stage 1	Clinical Stage 2	Clinical Stage 3	Clinical Stage 4
			~Moderate unexplained malnutrition not responding to standard therapy	~Severe unexplained wasting or stunting or severe malnutrition unexplained and not responding to standard therapy
Symptom/sign	No symptoms or only: Persistent generalized lymphadenopathy	~Unexplained persistent enlarged liver and/or spleen ~Unexplained persistent enlarged parotid ~Angular cheilitis ~Minor mucocutaneous conditions (e.g. chronic dermatitis, fungal nail infections or warts ~Chronic/recurrent URTI (sinusitis, ear infections, pharyngitis, tonsillitis ~Herpes zoster ~Recurrent mouth ulcers	~Oral thrush ~Oral hairy leukoplakia ~Unexplained and unresponsive to standard therapy: Diarrhoea, thrombocytopenia, neutropenia or anaemia ~Recurrent severe bacterial pneumonia ~Pulmonary TB ~TB lymphadenopathy ~Symptomatic LIP ~Acute necrotizing ulcerative gingivitis-periodontitis	~ Òesophageal thrush ~Herpes simplex ulceration> 1 month ~Severe multiple or recurrent bacterial infections ≥ 2 episodes in a year (not including pneumonia) ~Pneumocyctis pneumonia (PCP) ~Kaposi sarcoma ~Extrapulmonary tuberculosis ~Toxoplasma ~Cryptococcal meningitis ~HIV encephalopathy

ARV Therapy	Indicated only if CD4 shows severe immuno-deficiency. < 11 months CD4<1500 cells 12-35 months CD4 < 750 cells 36-59 months CD4<350 cells 5 years or older CD4<200 cells	Indicated only if CD4 shows severe immuno-deficiency. < 11 months CD4<1500 cells 12-35 months CD4 < 750 cells 36-59 months CD4<350 cells 5 years or older CD4<200 cells	ART indicated if child <12 months or if CD4 shows severe immune-deficiency ≥ 12 months If CD4 is not available, consider ART for all children with clinical stage 3. In general those with only LIP, oral hairy leukoplakia, TB confined to the lymph nodes or low platelet count are not as immunodeficient as those with other stage 3 illnesses.	ART indicated irrespective of CD4 count. If HIV infection cannot be confirmed, presumptive diagnosis of severe HIV disease can be made and ART started.

Note: Any one condition in the highest staging determines stage; clinical staging can only be performed if HIV infection is confirmed.

Adapted from WHO Case Definitions of HIV for Surveillance and Revised Clinical Staging and Immunological Classification of HIV-Related Disease in Adults and Children (WHO, 2007) pp.15-18

Although it would be helpful to know what factors might predict the rate at which children progress in HIV disease from one stage to another, no such defining criteria have as yet been identified. The National Institute of Allergy and Infectious Disease is currently supporting a study in Thailand to retrospectively analyze data on 300 children with varying CD-4 counts to determine if certain blood factors can provide some predictive clues (CRISP, 2007).

One symptom of HIV disease in children is the impact of the virus upon neurological and cognitive functioning. Brown, Lourie, and Pao, (2000) and others have

tied developmental or neurological deficits to the progressive encephalopathy- associated reduction in brain growth characteristic of HIV disease. In a 1994 study of 86 HIV infected ARV- naïve children, 44 % functioned at a below average level of intelligence, and 56% suffered significant language impairment (Papola, et al., 1994, in Brown & Lourie, 2000). A 1998 study by Bachanas, Kullgren, Morris and Jones, as well as a chart review by Brown and Lourie with older infected children not on ARV, found poor results on the WISC-3 as well as visual motor skills tests, results that conformed to CT scan revealing brain deterioration (Brown & Lourie, 2000). A longitudinal multicenter study of infected 3-7 year old children living in the United States revealed several important findings, including correlations between the age of a first AIDS-defining illness and encephalopathy, as well as cognitive development that was negatively correlated to stage of disease (Smith, et al., 2006). Although some gender correlations between neurocognitive functioning of HIV-infected children have been reported, these have not been sufficiently substantiated in the literature (Smith, et al., 2006). In addition, there is a postulated link between brain dysfunction and mood disorders in HIV positive children, but no substantive research supporting this link could be found. The good news about neurocognitive functioning is that if a child is started on ARV's, there is evidence that function can be increased or at least stabilized (Shanbhag, et al., 2005).

Pain is a common attribute of HIV/AIDS infection (Brown, et al., 2000). A study performed with 61 Thai children aged 4-15 found that 44% of the children described pain in their abdomen, lower limbs, or head (Lolekha, et al., 2004). In a study performed in the United States in 2002, the prevalence of pain in children with HIV disease was positively

correlated with lower CD-4 consistent with stage 3 or 4 disease, and female gender (Gaughan, et al., 2002). Pain can contribute to the quality of an ill child's life, and will be explored in this context further into the literature review.

Diagnosis and Treatment of Pediatric HIV/AIDS in the Developing World

The most commonly utilized test to determine HIV status is identification of the presence of antibodies to HIV, rather than presence of the virus itself, in the blood. This test becomes reliable in identifying antibodies produced solely by the child at approximately 18 months of age, when maternal antibodies are believed to have been excreted from the body if breastfeeding has been discontinued at least 6 weeks prior (Etiebet, et al., 2004). Following a positive antibody test, in areas where medical technology is limited, a CD-4 measurement is made in order to assess the number or percentage of healthy helper-t lymphocytes, specialized white blood cells that are present and available to fight secondary infections (WHO, 2007). It is the CD-4 count and the confirmation of any AIDS defining conditions that allow for treatment protocols based upon the internationally recognized HIV/AIDs clinical staging (WHO, 2007). Implementation of the treatment protocols described in the WHO document are differentially applied in individual countries (Tanzanian Commission for HIV/AIDS, 2002).

Kinoti's 2005 investigation into the availability of care for HIV infected children in Tanzania revealed that the care of these children had not been fully integrated into some hospital systems, and was severely lacking in others. He found that pediatric- sized supplies were often out of stock and that poor coordination of care often led to late or

inappropriate triage for infected children (Kinoti, 2005). Although the Tanzanian Ministry of Health has increased its focus on chronic pediatric HIV/AIDS care since the availability of antiretroviral drugs for children began in 2005, many systemic problems still exist.

Antiretroviral Therapy

A child living in Sub-Saharan Africa who has a CD-4 count of 200 or below and other conditions that determine they are at clinical stage 3 or 4 in WHO Pediatric HIV Clinical Staging is treated with antiretroviral therapy in addition to anti-bacterial or anti-fungal agents for secondary infections (WHO, 2007). The earlier in disease progression that antiretroviral therapy is begun, the better the outcomes, such as increased life span, children experience (Bolton-Moore, et al., 2007). Thorne's presentation at the 14th Conference on Retroviruses and Opportunistic Infections (2007) reported that most infected children in resource limited settings were started on ARV's at older age and later stage in disease than their counterparts in the developed world since their HIV status was not confirmed until they arrived for medical care for some symptomatic infection. That said, the utility of ARV's was borne out by his studies in South Africa, where 90% of children between 5 and 8 years old who began ART were alive 2 years later (Thorne, 2007). One concern Thorne cited was the issue of toxicity that may occur with long term antiretroviral therapy and which has yet to be investigated.

Antiretroviral treatment of children is the means by which life span can be

extended. In resource limited settings, single dose combinations are the standard treatment (Doctors Without Borders (MSF), 2006). MSF (August, 2006), in their report at the XVI International AIDS Conference in Toronto, Canada, decried the higher cost of pediatric over adult formulations and the very few adapted treatment modalities for children. Eley and Nuttall (2007) cited the magnitude of the pediatric HIV epidemic and the competing interests of adult care as contributory factors in the late and often inadequate attention to pediatric patient needs. The effectiveness of antiretroviral agents cannot be denied. For instance, in a 12 month study of 238 HIV infected Malawian children who began antiretroviral treatment, all showed weight gain and diminished incidence of secondary infections, even though 88.3% of them were already at stage 3 when treatment began (Ellis & Molyneux, 2007). Some critics have expressed concern that the poor infrastructure that exemplifies many Sub Sahara African health systems may not be able to appropriately manage antiretroviral treatment. However, Ellis and Molyneux (2007) and others provided research supporting the feasibility and effectiveness of anti retroviral treatment of children with only basic monthly clinical monitoring. The newest guidance from WHO makes possible simplified delivery of antiretroviral therapy even in areas with poorly developed health care systems. They support use of the lowest level of healthcare worker, whether in the hospital or the community, who can reliably be expected to perform chronic HIV disease management. (Gilks,et al., 2006).

Many of the children who could benefit from antiretroviral treatment are not receiving it. The UNAIDS report on progress made to address the Tanzanian AIDS

epidemic estimates that only 18 % of children who were in need of ARV's in 2006 received them (UNAIDS, UNICEF, & WHO, 2007). This state of affairs is a function of poor medication availability as well as poor access to care. Little et al. (2007) pointed to the limited amount of current information on pediatric HIV disease progression and mortality in Sub Saharan Africa, where widespread distribution of ARV's has only recently begun. In Tanzania, these medications finally became available to 10% of the children in need late in 2005, with increasing numbers being treated since (Unite for Children Report, 2006).

Treatment for Opportunistic Infections

Cotrimoxazole is an antibiotic that has been shown to be quite effective in the prevention of pneumocystis pneumonia and several other opportunistic infections associated with diminished immune system function. A Cochrane Review by Grumwade and Swingler in 2005 found that administration of cotrimoxazole, an antibiotic, is an inexpensive and effective way to support children who are immune compromised, whether they are taking antiretroviral medication or not.

Nutrition

Another avenue for treatment of HIV infected children is attention to nutrition. Because HIV infection is linked to chronic and often intractable diarrhea or other metabolic conditions, wasting syndrome, and oxidative stress, many of these patients suffer from malnutrition or deficits in vitamins, minerals, or other micronutrients (Kassu, et al, 2007Suttajit, 2007;). Anabwani and Navario (2005) asserted that malnutrition is linked to impaired development, and called attention to the need for nutritional

supplementation to support HIV infected children. This is often a daunting task in poor households, so many practitioners provide the recommended supplementary vitamin A and other micronutrients for infected children, and recognize that increased caloric intake may be a goal that cannot be met. Hunger is an often overlooked side effect of antiretroviral treatment, and HIV infected children not only desire more food as the body begins to respond, but are taking medications that must be ingested with food (Hardon, et al., 2007). In addition, some children presenting with HIV disease are malnourished or wasted because of the toll of unmitigated diarrhea and other metabolic impacts of the infection (Anabwani & Navario, 2005).

Medication Adherence

Adherence is the biggest challenge to medication-based treatment of children with HIV disease As a chronic disease, HIV/AIDS requires continuous medication to sustain the health of the patient (Chi, et al, 2007). However, special conditions apply to children who must take medication for a widely stigmatized disease. Roberts (2005) identified six main barriers to children's adherence to antiretroviral therapy. They are (a) interruption of daily routine, (b) side effects, (c) taste or size of the medication, (d) stigma related to the disease being treated, (e) reminders of the disease, its implicit death sentence, and fatalism, and particularly for caretakers (f) issues about disclosure and deception (Roberts, 2005). Elise et al. (2005) performed an assessment of pediatric antiretroviral medication adherence in Cote d'Ivoire at the very beginning of availability of these drugs in Africa. Their study showed that 1/3 of patients were not fully adherent, although compliance was better among younger children who were less aware of the meaning

implicit in taking these medications (Elise, et al., 2005).One additional aspect of this problem described by Hardon et al., (2007) is that it is usual practice in Africa to dispense a single month's medication at a time, which places a variety of burdens, as noted earlier, upon family members who must travel with the child to the clinic to collect the drugs. A meta-analysis of 11 electronic databases and 27 conferences in Sub Saharan Africa resulted in a pooled estimation of 77% adequate adherence in adult African ARV users (Mills, et al., 2006). No such data is available for the pediatric population. The risk in poor adherence is the development of drug resistance that makes for reduced utility of the first line drugs and increases the need for the more expensive second line (Hardon, et al., 2007). Most Sub-Sahara African nations offer only 2 lines of anti-retroviral treatment, so the patient who develops a strain of HIV that is resistant to both lines is no longer treatable.

Side effects are a commonly cited barrier to ARV adherence. Hardon et al. (2007) found that some patients are not informed by health care workers that side effects will usually diminish with time, leading them to discontinue treatment due to discomfort. Some researchers report that the side effects of these drugs are less pronounced in children than adults. For instance, the incidence of lypodystrophy, a commonly cited complaint in adults, is very low in children on ART (Van Rossum, Fraaij, & de Groot, 2002). A review of 23 clinical trials of pediatric treatment found only mild gastro-intestinal side effects which usually diminished with time (Van Rossum, et al., 2002). However, Gonzalez (2008) noted an increase in kidney problems in children on ARV therapy, and expressed concern for the long term effects of the treatment. Johnson and

Folkman (2004) reminded us that the side effects of treatment of a disease may be as important as the symptoms of the disease to the sufferer, and ought to be independently addressed.

Issues Surrounding HIV Diagnosis Disclosure to Children

Infection with HIV places the African child under psychological stress, and caretakers with increased burdens of several types. Much debate surrounds issues related to disclosure, since there is concrete support for the psychological importance of disclosure to children living with chronic illness (Brown & Lourie, 2000). One aspect of this debate is the correlation of disclosure in the presence of positive adult relationships with medication adherence (Bronw & Lourie). When HIV infected children live in a household with open communication they enjoy increased emotional health and better adherence to medication regimes (Bikaako-Kajura, et al., 2006). In a series of interviews with 42 Ugandan children who were aware of their status, open communication was supportive of all aspects of living with HIV (Bikaako-Kajura, et al., 2006). Waugh's (2003) work found that the actual disclosure was less important to the emotional health of children than giving them information and explanations that assist the child in making sense of their illness-related experience.

Abadia-Barrero and La Russo (2006) provided a description of an HIV disclosure model that is developmentally based and was utilized with 36 children living in or out of orphanages in Brazil. On the basis of their findings, the researchers postulated that as they age, HIV positive children are increasingly confused about the "interconnected meaning of sickness and taking medication" (Abadia-Barrero & La Russo, 2006, p.36)

and without communication can develop trust issues that may negatively affect psychosocial development in addition to the development of successful coping mechanisms (Abadia-Barrero & La Russo, 2006).

Their model suggested that if age appropriate information is given across childhood there is no need for disclosure concerns and the attendant emotional distress felt by both child and caretaker surrounding HIV status and treatment (Abadia-Barrero & La Russo, 2006). In interviews with 7-9 year olds, Abadia-Barrero and Castro (2006) found that this age group perceived the word AIDS and or the concept of being sick as negative, but were confused about what the terms meant in their own lives. Interviews with slightly older pre-adolescents revealed that the children were beginning to understand, and were reacting with shame and anger at the conditions of their lives (Abadia-Barrero & Castro, 2006). The adolescents interviewed exhibited poor understanding of the implications of living as an adult with HIV, and were dismissive of the importance of continued health care and (Abadia-Barrero & Castro, 2006) Although the situation regarding disclosure to HIV infected children may be different between developed and less developed countries, the fears and attitudes among parents and caretakers seem universal. A study in England revealed that parents were afraid to reveal the information to their children for fear that they would accidentally reveal their status, and thereby the parent's infection, subjecting the family to possible discrimination (Waugh, 2003). In a review of the records of 54 American children, 43% had been disclosed to at an average 9 years of age (Mialky, et al 2001), and by the age of 12 years the entire cohort was aware of its status. However, only 23% of these caretakers had

disclosed the child's HIV status to the school, which does follow the American Academy of Pediatrics support of the right to family choice in matters of public disclosure, but reveals fear of discrimination by outsiders (Mialky, Vagnoni, & Rutstein, 2001).

Those who have worked in Africa have described their experience with both caretakers and HIV infected children in the disclosure process. One set of focus groups of caretakers in South Africa revealed that the adults avoided discussing the infection despite the fact that the children often asked questions about why they were taking medicine or were often ill (Kouyoumdjian, Meyers, & Mtshizana, 2005). The researchers found that fear of stigma, lack of personal knowledge to answer the questions, as well as caretakers' own emotional unpreparedness were factors in the lack of disclosure (Kouyoumdjian, et al., 2005). The conclusion was that there is a huge need for social support of these adults so that they feel equipped to provide necessary education to the children in their care (Kouyoumdjian, et al., 2005). The Canadian Government's South African AIDS Trust document *Guidelines for Counselling Children Who Are Infected with HIV or Affected by HIV and AIDS* (2003) supports initial discussions with HIV infected children at 5-6 years, with increasingly specific information shared as the child ages. This viewpoint was supported by a survey of healthcare providers working in South Africa in 2006 (Myer, Moodley, Hendricks, & Cotton, 2006).

Subsequent counseling needs of adolescents were addressed by Strydom and Raath in their 2005 study in South Africa. They described the importance of emotional support as crucial to the process of exploration of long term life choices with infected

young adults (Strydom & Raath, 2005). Ledlie (2001) also explored psychosocial needs of HIV infected adolescents, particularly as they begin to transition into personal responsibility for medication adherence and self-care as well as dating. Ledlie's interviews revealed that, since adolescence is a time for asking many questions about the developing self, the home must be a safe place in which to explore anger at the mother who infected them, questions about why they have been punished with a lifelong chronic illness, and the opportunity to develop the necessary skills to function in the wider society (2001). For example, a case study of an HIV infected American adolescent revealed that the aunt/caretaker was reticent to disclose the nature of the child's disease to him for fear that he would become depressed and judgmental of his deceased mother (Lewis, Kitchener, & Burris, 2001). It was because he was an adolescent who was becoming interested in sex that he needed the vital information necessary to protect himself and future sex partners. As an increasing number of HIV positive children live into adolescence and young adulthood, new research is needed to understand their medical, emotional, and educational needs so that they are equipped to function within their society.

Psychological Function in HIV Infected Children

Brown & Lourie (2000) explored the psychological stressors and manifestation of psychiatric dysfunction attendant to pediatric HIV infection (2000). Their investigation of 84 HIV positive children found an association between poor emotional functioning, social support and school performance. The psychological status of the children was confirmed by elucidation of their anxiety and depression levels, as well as self- reported

physical problems such as pain or sleeplessness (Brown & Lourie, 2000). Lee, Gortmaker, McIntosh, Hughes, and Oleske (2006) found HIV infection to be associated with significantly lower mean adjusted functional status in a comparison of 1847 infected against 712 uninfected children of age 6 months to 4 years. In children 5 to 11 years, the impact was observed in health perceptions as well as self reported perceptions of physical and social role functioning (Lee, et al., 2006). Storm et al. (2005) studied 940 American children on antiretroviral treatment, and found no perceivable negative effects of the therapy on quality of life, but noted increased quality of life as physical strength and emotional resilience increased. They did caution, however, that poor physical endurance in sports and smaller stature may impact how a child sees themselves in relation to his uninfected peers (Mialky et al., 2001; Storm, et al., 2005). Additionally, they raised the question of how to minimize the perceptions of life-long disability associated with chronic disease (Storm et al., 2005).

One of the factors in describing the quality of life of HIV infected children is assessing the effect of negative events unrelated to their own disease. Many African children suffer the death of their parents, the necessity of moving in with relatives or unrelated caretakers, or other impactful circumstances such as living in poverty that may manifest in behavior problems or other symptoms of distress (Howland, et al., 2007). In their longitudinal study of 1018 HIV infected children, Howland, et al. (2007) found that when a child had 1 or more negative events in the last 12 months there were significant changes in the child's perception of their own health and quality of life.

Orphanhood in Sub Saharan Africa

Andrews, Skinner, Zuma, and Khangelani described three areas of dependence created by the experience of AIDS orphanhood in Sub Saharan Africa (2006). They are (a) the material realm of basic needs like food and shelter, (b) the emotional experience of love, care, and a safe place to grieve, and (c) the social context including a supportive friendships, adult mentors, and freedom from stigma (Andrews, et al., 2006).

Grassly et al. (2004) made a comparison of reported and actual causes of death that led to orphanhood in South Africa. They concluded that, because AIDS is widely stigmatized, it is grossly underreported as the cause of death, which impacts the validity of estimates made of the percentage of children actually being orphaned by AIDS rather than other causes of parental death (Grassly, et al., 2004). Children who are orphaned by AIDS see their life circumstance differentially depending upon the local meaning of the infection. A participant observation study in Mwanza, Tanzania of 158 person-weeks duration found causation variously defined as "God's will, ancestral spirits, chance, natural biological, and witchcraft" (Mshana, et al., 2006, p 45). Many of the persons interviewed had not heard of HIV, but knew that AIDS was caused by sexually transmitted infection (Mshana, et al., 2006).

To be a child who has lost a parent to a disease often defined as spiritually-linked can breed discomfort and fear that they have been similarly bewitched. A case study of 8 Ugandan orphans 11-15 years conducted by World Vision that was included in the United Nations Study on Violence Against Children found that self-stigma was endemic among the children and that community abuse seemed to conform with the children's

vision of themselves (World Vision, 2005).

In these countries, children of mortally ill parents, whatever their age, are expected to care for the parent during their illness, and in the case of AIDS there may the subsequent death of a second parent (Crampin, et al., 2003). Ngalula, Urassa, Mwaluko, Isingo, and Boerma (2002) described the economic costs of AIDS illness and death in rural Tanzania. Because AIDS is not an acute illness, the duration of traditional and western health care were measured as costing 1.5 times more than cancer or other terminal illnesses (Ngalula, et al., 2002) Funerals are also very costly, and the authors stated that in many cases the medical and funeral expenditures are measured at more than the annual income of the household (Ngalula, et al, 2002; Nyambedha, Wandibba, & Aagaard-Hansen, 2003)

After the death, many households are left with debt and economic insecurity. Moszyski described the lack of formal assistance to these children during the final stage of their parent's illness, and the negative impact of caring for sick relatives on the children's own educational and developmental needs (2006). He was joined by Kidman, Petrow, and Heymann (2007) in decrying the scarcity of interventions in Sub Saharan Africa that provide emotional support to potential orphans or their communities.

The effects of parental death in Africa were measured in a 10 year retrospective study in Malawi, and ranged from the inability to attend school to malnutrition, homelessness, and the debilitating impact of grief (Crampin, et al., 2003). Miller, Gruskin, Subramanian, and Heymann (2007) looked at the weight disparities between AIDS orphans and other children using anthropomorphic data on 2733 children under 5

years living in Botswana. They found that the orphaned children under 4 years were 49% more likely to be underweight, controlling for household poverty and other possible contributing factors, and that they were more likely to live in poorer households (Miller, et al., 2007). This state of affairs exists partly because of the variability of orphan placements and thereby the inability of social service entities to create models for programming. Hosegood, et al(2007) retrospective study of orphan placement based upon 2002 data helped to describe the patterns within Tanzania, Malawi, and South Africa. In any case, the rate of orphanhood due to the AIDS pandemic has not stabilized, and the diversity of living arrangements for these children places burdens upon families, communities, and those who would support them throughout Africa (Hosegood, et al., 2007).

Orphan Placement

The care of a child subsequent to parental death is usually first the responsibility of extended family, and then moves to informal guardianship or institutional placement. Freeman and Nkomo (2006) interviewed parents living with AIDS about their intention for after death care of their children. Twenty eight percent believed either their partner or a grandparent would care for the children, 25% believed another family member would do so, and 12% could not identify an appropriate caretaker (Freeman & Nkomo, 2006). Seventy one percent of family members interviewed agreed to care for the children after the death, but the authors expressed concern that the intention might not translate into action (Freeman & Nkomo, 2006). It must also be remembered that loss of an adult child has negative impact upon their parents who may be elderly, suddenly without financial

support, and expected to care for grandchildren (Dayton & Ainsworth, 2004). A study in Tanzania confirmed the expectation that grandparents would be the most likely caretaker (Makame, Ani, Grantham-McGregor, 2002). Barnett (2006) decried this state of affairs, pointing to some African parents who "live just long enough to reproduce and die", leaving the long term impact of their actions upon the shoulders of family and society and their children without the connection to and support of parents (p.304).

Guardianship of AIDS orphans has changed as the pandemic has developed. In 1999 data on 241 Ugandan orphans, Sarker, Neckermann, and Muller (2005) found that, at that time, families were still able to absorb the number of orphans in need of homes. However, a 2003 study in Kenya to investigate the impact of large numbers of orphans in need of care as a result of the AIDS epidemic found that, at the time of this study several years later, 28% of orphaned children were being cared for by culturally inappropriate guardians, such as matrilineal relatives or non-family members (Nyambedha, et al., 2003). This situation has developed as the sheer numbers of orphans exhausted the available number of what are considered culturally appropriate caretakers (Nyambedha, et al., 2003). Beard investigated orphan living arrangements in Malawi (2005). He found that his sample uniformly preferred community-based care in the absence of available or suitable family because it keeps orphans connected to their home village and tribe (Beard, 2005). The fear, based upon experience, is that there may be long term impact on kinship ties and land inheritance when non-related caretakers assume responsibility for orphans (Madhavan, 2004).

In a South African study designed to test the theory of planned behavior as it relates to care for unrelated AIDS orphans, Townsend and Dawes (2007) reported 76% of potential foster parents were willing to care for an HIV negative child, and 62.2% were willing to care for an HIV positive child. The study found, however, that the theory was not useful in explaining the multiple factors involved in making such a decision (Townsend & Dawes, 2007).

A debate that continues in the social service community surrounds the question of whether orphans ought to be treated as a special class of vulnerable children. The African contextual definition of an orphan is a child who has lost at least one parent, since the impact on a child or household can be as great with the loss of even one wage earner (Chuma, Gilson, Molyneux, 2007). UNAIDS defined an orphan as a child under 15 years who has lost either a mother or both parents (2006). The definition went further to describe the conditions surrounding orphanhood in poor access to food, shelter, support, and love (UNAIDS, 2006). Skinner, et al., (2006) and Henderson (2006) provided the argument that these factors extend to all vulnerable children, defined as those lacking in basic needs or rights, not just those who are orphaned, since poverty, drought, disability, or political oppression can result in the same impact upon the lives of children as orphanhood. The concern is that overemphasis in the donor community and media on AIDS orphans objectifies them and makes them subject to stigma, and at the same time overlooks the same needs in other children. There is also the fact that some AIDS orphans enjoy relatively comfortable lives (Skinner, et al, 2006; Henderson, 2006). Meintjes and Giese (2006) saw the concept of AIDS orphan as a stereotype that could

negatively impact the work of low income countries to meet the needs of all vulnerable children (2006).

In 2005, Whetten began an NIH sponsored longitudinal investigation on the long term placements of AIDS orphans in Cambodia, Ethiopia, Kenya and Tanzania. Her study will follow the children for 4 years to determine the factors that are linked to positive outcomes in children who are placed in relative and non-relative homes rather than orphanages, where much of the previous research has been performed (Whetten, 2005). Another ongoing investigation is being performed in Lesotho, where Short is investigating the long term effects of parental death and relative child disadvantage as it derives from issues within the family**.** He is using schooling as the outcome variable, since orphans often live in homes where school fees are economically unavailable, the child must work in the home to earn their keep, or the child is viewed as a burden and not supported in educational aspiration (Robson & Sylvester, 2007). Bhargava and Bigombe (2003) supported the idea of subsidies, as is done in South Africa, to those who care for orphans that will enable the children to attend school and not tax the resources of the host family (2003).

Orphanages

A secondary placement for AIDS orphans is in orphanages. Although the benefits of living with family are widely supported, there are situations where children either must live in residential facilities or be cast out upon the street. An unpopular position espoused and supported by Zimmerman's 2005 study in Malawi showed that, in the short term, children living in orphanages enjoyed greater quality of life than those in foster

placements. Kodero (2001) compared anxiety levels and whether the education and emotional needs of AIDS orphans were being met in various types of placements. His study in Kisumu, Kenya found that orphanages did the best job, and extended family did the poorest, in meeting the children's needs (Kodero, 2001). Particularly for children who are HIV infected and ill, chronic care may be better managed by staff of a specialized orphanage than by uneducated and impoverished caretakers.

Psychosocial Impact of AIDS Orphanhood

The psychosocial well being of AIDS orphans enjoys continued research. An important study by Cluver and Gardner (2007) resulted in a matrix that illustrated the intertwined risk and protective factors to psychological well being of AIDS orphans. Using urban South African children and their caretakers, the researchers worked to tease out the difference between the general effects of poverty and those related specifically to AIDS orphanhood. Cluver and Gardener's (2007) study also measured depression, anxiety, post traumatic stress disorder, peer problems, and conduct difficulties in 1025 children. The research found that AIDS orphans suffered higher prevalence of these problems that children orphaned by other causes and non-orphans. (Cluver & Gardner, 2007). They confirmed previous data that AIDS orphans exhibited significantly higher rates of suicidality than other children (Cluver & Gardner, 2007). In African children, AIDS orphanhood has been related to internalizing of psychological stress rather than external manifestation through conduct problems (Cluver & Gardner, 2007). The results on depression and internalization confirmed those found by Atwine, Cantor-Graae, & Bajunirwe (2005), who performed the Beck Youth Inventories on 123 Ugandan AIDS

orphans.

Makane, Ani, Grantham-McGregor (2002) performed a study comparing the psychological well being of 41 AIDS orphans to 41 non-orphans living in the same neighborhood in Dar Es Salam, Tanzania. Using internalizing problems as the primary indicator of psychological stress, Makame et al. (2002) found correlations in the orphans that were not present in the other children between several self described conditions, including "(a) going to bed hungry, (b) no reward for good behavior, and (c) not attending school" (p. 459). Secondary findings were that 34% of the orphans had contemplated suicide in the last year, that problems were more prevalent in female than male orphans, and that the greatest levels of distress were found in children less than 13 years (Makame et al, 2002). Howard, Matinhure, McCurdy, and Johnson's work with orphans in Zimbabwe revealed that most of the children received no emotional support in mourning their parents, which led to feelings of isolation and inferiority (2006). Their data, confirmed by Andrews, et al (2006) also suggested that the combined stressors of orphanhood and economic disadvantage create the climate for poorer psychological as well as physical health (Howard, 2006). The extensive research on this topic supports generalizability of these findings to AIDS orphans living in Sub Saharan Africa, including Tanzania.

Pediatric Chronic Disease

In the era of antiretroviral medication, HIV/AIDS has become a chronic disease. Boekaert and Roder, in their review of the literature related to chronic disease in children, used the definition of chronic disease proposed by Eiser: "conditions that affect children

for extended periods of time, often for life. These diseases can be managed to the extent that a degree of pain control or reduction in attacks…can generally be achieved. However, they cannot be cured" (1999, p. 311). In many ways, children living with HIV/AIDS in any country suffer the same challenges as those living with birth insults, congenital defects, or diseases like asthma or diabetes. Children living in the developed world have access to an ever-increasing set of antiretroviral therapies that may increase longevity and minimize the impact the disease has on quality of life (Bernardi, et al, 2000). Because children suffering from AIDS in developed countries have had access to ARV's for 15 years or more, a greater volume of research exists on these children (Bernardi, et al, 2000). This section will explore investigations into pediatric chronic disease to identify underlying themes useful in describing the world of the HIV infected child.

Chronic Disease Constructs

In the 1970's, medical sociologist Strauss and Glaser (1975) began to investigate the experience of dying, and subsequently the experience of living with chronic disease. They postulated a longitudinal model, the Corbin and Strauss Chronic Illness Trajectory Framework, which incorporated the events and attitudes that are the substance of the necessary continual adaptation to chronic illness (Burton, 2000). The model recognized not only the physical and psychological implications of the illness, but also the inherently social nature of living with chronic disease (Corbin & Strauss, 1988). Living with chronic illness necessitates a variety of social interactions with others, from caretakers who are intricately linked to the needs and processes of the patient, to the stigma that may be

generated from the wider world (Strauss & Glaser, 1975). In work with Corbin, Strauss further developed his model to include delineation of the three types of work that are done by the person with chronic illness (Corbin & Strauss, 1988). These include the illness work, management of everyday life tasks, and what he calls the biographical work, which encompasses the psychological work of defining and subsequently accepting the meaning of life with chronic disease (Corbin & Strauss, 1988**)**. As the chronic illness moves through the trajectory, medical crises and the natural course of the illness necessitate social adaptation by all of those others who are peripheral to the patient, making it a complex social system. Recent recognition of the usefulness of the model has spawned disease-specific descriptions of illness trajectories in the desire to generate social and institutional support for patients, families, and professionals (Burton, 2000).

Charmaz worked with Strauss in the study of chronic illness, and then followed her own path in the investigation of the interplay between living with chronic disease and the sense of the self over time. Her construct divides the experience of chronic illness into three steps, each with their own attendant qualities and challenges (Charmaz, 1983). In the first stage, the patient believes the illness to be an interruption in their normal life, which will have an endpoint (Charmaz, 2003). In this stage, the individual is able to maintain their view of themselves as a person of value because the interruption is temporary and there will be a restoration of independence and productivity (Charmaz, 1983). The second stage is characterized as an intrusion, which increasingly demands attention and adjustment in many areas of life, and reveals the previously held self-concept to no longer be congruent with the way the person experiences their days

(Charmaz, 1983, 1991). The challenge of this stage is the destruction of the previously held view of the self as valuable, and the need to create a new view that incorporates the limitations of the illness in the present (Charmaz, 1983). Charmaz reminded us that choice and freedom, the bases for much self definition, become less possible with the restrictions of living with chronic illness (1991). In the third stage, which Charmaz calls immersion, the sufferer incorporates the chronic illness into their self-description (1991). The illness drives the activities and life of the individual, and forces attention to the day being lived as the only focus (Charmaz, 1991). The previous self is gone, and the future is an unknown. This cycle is typically repeated many times, with the ebb and flow of the illness progression. Charmaz's investigation into the social consequences of disclosure of chronic illness will be described in the section on stigma.

Chronic Disease Responses in Children

In 2000, Brown and Lourie delineated the ways in which understanding children with other chronic diseases were helpful to understanding children and youth who live with HIV and AIDS. They identified the unique psychological stress that manifests in anger or hopelessness, as well as perceived external locus of control, as common characteristics found in children with chronic disease (Brown & Lourie., 2000). Kaminsky, Robertson, and Dewey (2006) then identified the coping style of children with recurrent abdominal pain and found primarily passive internalized strategies such as isolating or disengagement that often manifested in depression. Their sample did, however, exhibit better self-efficacy with increased social support and maternal adjustment (Kaminsky, et al., 2006). In another study performed with children aged an

average of 10.6 years and suffering functional abdominal problems, Jellesma, Rieffe, Terwogt, and Kneepkens (2006) found that children with physical problems suffered increased rates of emotional impairment manifested as depression and mood disorders. This finding can be analyzed in terms of other studies, such as that done on 52 children post bone marrow transplantation for cancer that correlated the quality of life of a child with a chronic health condition to their self-rated symptomatology (Forinder & Winiarski, 2005).

Chronic Disease-related Depression

Kiviruusu, Huure, and Aro (2007) looked at vulnerability to depression in a sample of 257 healthy or chronically ill adolescent males and females suffering from diabetes, asthma, or migraine. They found no difference between sick and well females, but decidedly different rates between chronically ill and healthy males (Kiviruusu, et al., 2007). The disparity in rates of depression were related to sex-linked coping mechanisms; chronically ill males with lower rates of depression exhibited more highly developed problem solving and the related internal locus of control, while chronically ill females with low rates of depression enjoyed higher levels of perceived social support (Kiviruuse, et al., 2007). Overall, this study points to significant gender disparity in the prevalence of depression among chronically ill young people (Kiviruusu, et al., 2007).

Meaning of Chronic Disease to Children

Local meaning of illness is also a factor in the quality of life of sick children, since it can affect both how they see themselves as well as the level and type of care that they receive by others in the household (Hildenwall, et al., 2007). In their paper

describing data collection methods for research on childhood illness, Byrne and Gregory (2007) pointed to the need to understand the local meaning and understanding of illness in each environment in order to properly describe or count cases and responses.

Gerhardt, Walders, Rosenthal, and Drotar (2004) observed how researchers approach the investigation of children with chronic disease. They decried the deficits-based models depicting the children as weak and vulnerable instead of concentrating on the adaptive behaviors these children exhibit that lead can lead to successful functioning (Gerhardt, et al., 2004**,** p. 173). These researchers pointed out that access to quality health care can provide the child with the support needed to deal with symptoms and adhere to medication, which subsequently leads to better quality of life (Gerhardt, et al., 2004). This attitude was supported by the teens interviewed by LeVert (1993), who cautioned chronically ill peers to always take their medication to avert potential health crises, and to trust oneself to know your own limits and potential. These young people repeatedly supported their right to the truth about their conditions and the progress of their disease as a way to manage the outcome or their attitude about outcome (LeVert, 1993). This finding joins the literature that supports early and full disclosure to HIV infected children. The interviewees for this book described loss of school days for medical care or illness and the sense of reduced opportunities in adulthood as the areas where they suffer the most distress (LeVert, 1993). The work by Hudsmith and Thorne (2007) supported a gradual transition into self-care that recognizes the dual burdens of chronic disease and adolescent struggles with questions of social functioning and identity.

The meaning of having a chronic disease varies with the disease itself, as well as the internal and external environmental responses to it. Gray and Rutter (2007) explored this interaction in children with chronic fatigue syndrome. They found that the ability to develop coping strategies mitigated the effect of the meaning of chronic disease upon the children's physical functioning and overall quality of life (Gray & Rutter, 2007). An earlier study that explored the impact of poor social self-efficacy supported a link to development of childhood depression with a greater incidence in girls, as confirmed by previously cited studies (Bandura, et al., 1999). Perrez and Reicherts (1992) argued that environmental context is a subjective variable in successful coping with disease-related stressors, a finding that supports the limited applicability of previous research on pediatric chronic disease in Western societies to this study in Tanzania.

Boekaerts and Roder (1999) reviewed studies that investigated the relationship between childhood maladjustment and chronic disease, but without conclusion, as the findings were variable across diseases and methodology. Additionally, there was no evidence of different stress-mitigating coping strategies between healthy or ill children, although chronically ill children utilized more cognitive and internalized techniques (Boekaerts & Roder, 1999).

Children Coping with Chronic Disease

According to Leventhal and Mora (2005), One of the most important contributors to living successfully with chronic disease is the ability of the individual to manage the interaction between the concrete experience of the disease, what they think about it, and what goals they set for it Leventhal and Mora (2005) postulate a longitudinal interplay

between the negative life events that present themselves and how one chooses to think about, and thereby act upon, them.

Folkman, Lazarus, and Dunkel-Schetter (1996) discussed the differential responses of the child at various stages in the disease process. The staging of these emotional responses was well delineated by Maes and Leventhal (1996). According to their system, children pass through the following 4 stages: (1) A stage of uncertainty, in which children try to conceptualize the disease, (2) a stage of disruption, in which they realize they are plagued by something that may last the whole of their life, (3) striving for recovery, and (4) restoration of well-being. (Maes & Levelthal, 1996, pp. 225-6)

Kovacs, Iyengar, Goldstone, and Stewart's (1990) longitudinal studies of children with diabetes demonstrated the mitigation of emotional distress over time dating from their initial awareness of the diagnosis. Another important variable in measuring coping and adjustment is the chronological and developmental age of the child (Boekaerts & Roder, 1999). Dubow et al., (1991) saw successful adjustment as an incrementally developed "social problem solving skill" (p. 583). A study designed to measure children's self concept was undertaken in Turkey with 77 children suffering chronic disease and a matched cohort with acute medical crisis (Gultekin & Baran, 2007). Although there were no statistically significant findings on self-concept between children with chronic or acute illness, diagnosis was the most important intervening variable, as those with hemato-oncological illness, including HIV/AIDS, scored poorly on self concept (Gultekin & Baran, 2007). The researchers cited the work of Er (1991) who correlated self concept to treatment period, and believed that their findings support this

contention in the length of treatment required as well as quality of life concerns expressed by their research population (Gultekin & Baran, 2007). The incidence of reported behavior problems also was higher in chronically ill than in acutely ill children (Gultekin & Baran, 2007). This correlation between behavior problems in chronically ill children, specifically HIV infected, was supported by the study performed in India by Grover, Pensi, and Banerjee (2007). In their matched cohort investigation of 140 HIV infected within a total 301 children aged 6-11, this group used the Child Behavior Checklist to reveal a behavior disorder rate of 80.7% in infected compared to 18.3% in uninfected children, as reported by primary caregivers (Grover ,et al., 2007). A cohort of 23 American children with diabetes was followed for a median 12 years into their early 20's (Gee, et al., 2007). Their emotions and attitudes expressed over time about living with chronic disease centered on the limitations the disease placed upon their life opportunities (Gee, Smith, Solomon, Quinn, & Lipton, 2007). Even with support, the youth were concerned about their need and ability to manage their disease in adulthood (Gee, et al, 2007).

Eiser (2004) described quality of life as a subjective measurement impacted by the multiple fields of experience within a child's life (2004). For instance, she describes the differential reporting she has encountered between children and their parents about the ill child's quality of life, even with the recognition that very young or very sick children may be cognitively unable to adequately provide good information (Eiser, 2004). Young, Rice, Dixon-Woods, Colver, & Parkinson (2007) used KIDSCREEN™, a validated health related quality of life instrument, to conduct in depth interviews with a

cohort of 28 children living with cerebral palsy. Although they obtained useable data from the instrument, they found that the children reported unrepresented yet related experiences that were not measured by KIDSCREEN™ (Young, et al., 2007). For instance, no items were included that assessed relationships with adults other than parents, relationships with family members other than parents, inclusion and fairness, home and neighborhood, or pain or discomfort (Young, et al., 2007). Quality of life, then, is a multi-dimensional concept which no current instrument has successfully been able to adequately assess.

Caretaker Adjustment to Pediatric Chronic Illness

Caretaker or parental adjustment to childhood chronic disease can be an important factor in how the child experiences his life. Among a sample of Thai adolescents suffering from asthma, positive family functioning was correlated to positive sense of self and resourceful coping, making the case for the impact of parental attitude upon the perceptions of the chronically ill child (Preechawong, et al., 2007). Work to support theories regarding parental sense of coherence about their chronically ill children derived from the records of 10,000 Nordic children, however, found that the relationship was disease or disability specific (Groholt, Stigum, Nordhagen, & Kohler, 2003). Positive parental functioning was investigated by Dewey and Crawford (2007), who found correlations for mothers to social and family support and correlations for fathers to cognitive understanding of the child's medical condition and treatment.

Hope

Hope is cited as an important component of quality of life in facing chronic disease. Snyder, et al., (1991) defined hope as "a cognitive process comprised of reciprocally derived sense of successful pathways , i.e., "the ability to visualize goals", and agency, i.e., "the determination to reach these goals." (p. 225) Venning, Elliott, Whitford, and Honor (2007) used the Snyder Children's Hope Scale (1997) to investigate the levels and factors that contributed to the experience of hope in children with congenitally or acquired chronic disease. In a sample of 132 Australian children and their parents, the group found higher scores on hopefulness in children with congenital illness correlated to the levels of self efficacy and social functioning, and higher scores in parents when the illness was acquired, which correlated to their self-efficacy and level of depression (Venning et al, 2007). In other words, the hope scores could be predicted by the source of the information. For the children, Venning et al., (2007) postulated that learning a diagnosis later in childhood can destroy the child's expectancies about their future, where children with congenital illness would never have developed hopes that could be dashed (Eiser, 1994). Previous research has suggested that the sources of hope in dealing with illness range from self efficacy to spirituality. Rodriguez-Hanley and Snyder (2000) proposed that hope is a phenomenon that occurs in the social realm.

Stigma

Crocker, Major and Steele (1998) provided a useful definition of a stigmatized person as one whose "social identity or membership in some social category calls into question his or her full humanity….the person is devalued, spoiled, or flawed in the eyes

of others." (As cited in Pryor, Reeder, Yeadon, & Hesson-McInnis, 2004, p.501). Charmaz (1991) described the experience of the chronically ill stigmatized person as being socially ostracized or ignored because of awareness or outward manifestation of the chronic disease. The magnitude of the impact of this experience is predicated upon the source, location, and frequency of negative social experiences (Charmaz, 1991). She further explored the potential risks of disclosure of chronic illness, which could contribute to loss of social status and concomitant isolation, as well as dislocation of the self (Charmaz, 2002).

HIV/AIDS is a stigmatizing disease across all cultures because sex is the primary agent of infection. Campbell, Nair, Maimane, and Nicholson (2007) performed 120 interviews and a series of focus groups in South Africa to determine the drivers of AIDS stigma. The most highly correlated attitudes were (a) fear of catching the disease, (b) the perceived link between the disease and sexual immorality, (c) lack of information, education or places for social dialogue, and (d) issues regarding control of women and youth (Campbell, et al., 2007). In their longitudinal study of AIDS orphans living in Malawi, Crampin, et al., (2007) discovered that even orphans who were not infected themselves were stigmatized by the cause of death of their parents. Discriminatory responses, however, are not limited to the behavior of persons living in undeveloped nations. In England in 2003, parents with HIV positive children who were themselves infected were often unwilling to disclose the nature of the child's disease for fear that it would lead to inappropriate disclosure of their own HIV status and create the potential for ostracism or other negative social responses (Waugh, et al., 2003). Children who are

infected perinatally are often shunned by peers and other adults who fear infection. Living with a stigmatizing disease creates psychological distress and social distancing in many people, and can be a major factor in quality of life. Hardon (2007) described the distress of HIV positive persons in Africa who have experienced discrimination simply based upon their need to take medication in public.

Dlamini, et al. (2007) provided a general definition of stigmatizing behaviors experienced by persons living with HIV/AIDS in 5 African countries, including Tanzania Among the responses were (a) avoidance, (b) verbal or physical abuse, (c) social isolation, (d) decreased access to work or services, and (e) rejection by family or friends (Dlamini, et al., 2007). These kinds of responses discouraged disclosure of infection by parents or caretakers to infected children, because the adults were unwilling to expose the children to the social ramifications of their infection, and were themselves often unprepared to deal with their emotions about HIV as a fatal disease (Kouyoumdjian, et al., 2005). Varga, et al. (2006) followed the progress of HIV infection disclosure among South African women who discovered their HIV infection during pregnancy or at the time of birth. Of the 93.5% who chose to tell someone, most told a partner (Varga, et al., 2006). However, secondary disclosure by that person to other family members or neighbors resulted in higher levels of rejection, withholding of support, and other manifestations of stigma (Varga, et al., 2006).

An instrument was developed in 3 stages between 2003-2006 by Holzheimer, et al. (2007) to test HIV/AIDS related perceived stigma in infected African populations. Pilot testing was performed in Lesotho, South Africa, Malawi, Swaziland, and Tanzania

with 1477 people after focus groups revealed the specifics of the African experience of HIV/AIDS stigma (Holzhemer, et al., 2007). The factors surveyed in the Holtzeimer instrument were (a) verbal abuse, (b) negative self perception, (c) health care neglect, (d) social isolation, (e) fear of contagion, and (f) workplace stigma (Holzhemer, et al., 2007). The authors felt that the factors measured by their instrument were more fully descriptive of the experience of stigma than those used by Berger, et al. (2001) in their earlier instrument or factors developed by the Tanzanian Working Group (2005), which utilized only community level stigma, health worker stigma, and PLWA stigma. Elements of the survey were used in this investigation to ascertain the levels of perceived stigma reported by the participants. Berger, Ferrans, and Lashley (2001) also supported the importance of developing instruments that are built upon local socio-cultural meanings and responses to HIV/AIDS.

Self stigma is an aspect of the unhealthy psychological functioning found in some pediatric AIDS patients. When questioned about the word AIDS, and the condition of being sick, a cohort of 7-9 year old HIV positive Brazilian children saw these concepts as negative, but were confused about what they mean in their own lives (Abadia-Barrero & Castro, 2006). In pre-adolescents, the researchers found shame and poor attitude toward the utility of treatment and their future (Abadia-Barrero & Castro, 2006). These researchers found that the experience of internal as well as external stigma changed as the children aged (Abadia-Barrero & Castro, 2006).Although these findings were common across the spectrum of chronic illness diagnosis, the source of HIV increases the risk of self-stigma in children. For example in India, Ponton and Lees (1998) found children's

knowledge of their infection with HIV was linked to “extreme reactions of shame, fear, humiliation, and anger” (p. 204).

Some persons with stigmatizing conditions have been found to develop higher, rather than lower self esteem and self-concept than might be predicted by some measures. Crocker, Major, and Steele (1989) described the development of self protective mechanisms, borne out by some empirical research that defy theoretical constructs about stigma predicting low overall self esteem. They define three elements of this process:

1. Comparing themselves to others within their group instead of between themselves and members of another group.

2. Choosing to devalue the elements of their self-description that lead to the social response.

3. Attributing the negative responses of others to the “prejudiced attitudes” among the others.

(Crocker, et al., in Hillman, Wood, & Sawlowski, 1998, p. 30).

Although this theory was developed regarding racial stigma, there are elements of the construct that are useful for investigating responses of HIV infected persons to the discriminatory behaviors of others as part of this description of the world of the HIV positive Tanzanian orphan.

The importance of examining stigma in terms of local ecology is illustrated by a study performed by Xiaobin, Sullivan, Xu, and Wu (2006) to examine the sources of AIDS related stigma in China. The results of 80 interviews confirmed that the worst negativity came from uninfected villagers who felt secondary stigma for the entire village

because infected persons lived among them (Xiaobin, et al., 2006). This group perception impacted those living with the disease differently than described in any other literature. In China, the sensibility of the HIV positive persons to having impacted the entire village brought both greater shame as well as greater concern for the discrimination shown toward their uninfected family members (Xiaobin, et al., 2006). Abadia-Barrero and Castro (2006) also supported the ecological approach, and saw HIV/AIDS stigma within "complex discrimination processes" endemic to cultural perceptions of the disease (p. 219).

Reproductive Rights

One area of discrimination encompassed by societal attitudes toward HIV infected persons is attitude toward sexual activity and childbearing in the HIV positive population. Of 843 South African women interviewed, only 43% felt that women with HIV should be able to continue to enjoy sex and only 13% believed they should have children (Myer, Morroni, & Cooper, 2006). These attitudes call into question issues of reproductive rights for the millions of children and adolescents who are growing up HIV infected, and have the expectation of marital relations and childbearing. The increasing availability of medical intervention to prevent perinatal transmission of HIV may decrease some these attitudes over time, but the concern about the spread of the disease to non-infected partners continues to be a matter of debate worldwide (Myer, et al., 2006).

Theoretical Constructs Regarding Coping Strategies

Several theories have been developed in attempts to identify and explain how some persons, and children in particular, seem to persevere in the face of negative events

while others do not. In this investigation, current research on resilience, locus of control, sense of coherence, and learned resourcefulness were utilized to provide theoretical guidance to the methods. The intent was not to support the theories, but to use elements of them as descriptors of some factors at play in the emotional lives of HIV- positive Tanzanian orphans.

Resilience

Resilience was described by Luthar and Cicchetti (2000) as "the dynamic process encompassing positive adaptation within the context of significant adversity" (543). The definition implies that the child adapts better than might be expected given the circumstance, and that the resilient response develops after the negative event has occurred (Friesen, 2007). The underlying idea that this response is provocation- driven was challenged by Masten (2001), who believed that the ability to be resilient is most often present rather than absent in most people unless there has been some interference by other factors either prior to, or at the time of, the adverse situation. Masten, Best and Garmezy (1990) described some of the qualities exhibited by resilient children as high intelligence, acceptance of life's challenges, and internal strength and directedness. Masten and Coatsworth (1998) added that supportive adult others who provide structure and high expectations are also important to resilience. Werner (1995) highlighted the protective factors supportive of resilience as (1) personal attributes, (2) close bond to a family member, and (3) community support. Bushweiler (1995) looked at Werner's (1982, 1995) longitudinal study of Hawaiian children to further describe the factors present in more resilient children. He found that the more resilient children sought help

only from trusted adults rather than institutional or formal sources, demonstrating their more independent nature Bushweiler (1995). In addition, his analysis revealed that school was a refuge for these children (Bushweiler, 1995). The characteristics and sources of resilience are variously defined and operationalized, and do not as yet present a coherent construct. Questions also remain as to whether adaptive functioning in one area constitutes resilience or if it must be evident in multiple dimensions. Also unanswered is the question of how we analyze the variability of adverse circumstances. It is hard to quantify parental death as worse than living in poverty. More questions exist around whether resilience is consistent and available over a child's life and circumstances. It may be that the study of resilience leads us to describe processes rather than provide definitions or confirm theory.

Ryff and Singer (2003) looked at the current research on resilient children, including the work by Werner, and described much of it as analysis of positive adaptation to challenges presented by the situation at home or by the external world. They called for extension of the investigation to internal negative circumstances, like chronic illness, rather than the concentration on external circumstances (Ryff & Singer, 2003). In addition, Gerhardt, et al. (2004) called for development of interventions to identify and capitalize on the strengths inherent in most children rather than concentration on their weaknesses (2004). Howard, et al. (1999) quoted Rutter's (1990) description of resilience as the "positive pole of the ubiquitous phenomenon of individual difference in people's response to stress and adversity" (p. 307). Their meta-analysis of resilience literature acknowledged Folkman, et al.'s (1986) contributions to understanding and

describing the way in which a resilient person manages, both cognitively and behaviorally, the interaction between the conditions of their life and their own sensibilities (Howard, et al., 2006). Yet they stressed the importance of performing these analyses within a cultural/social context instead of approaching them as if they occurred without these influences (Howard, et al., 2006). For example, Magaya, Asner-Self, and Schreiber (2005) utilized three well respected instruments to assess coping strategies in Zimbabwean adolescents. Results from the Ways of Coping Scale showed more coping strategies that were emotion derived than cognitively derived (Magaya, et al., 2005). What could not be determined was if this was the culturally embedded technique for coping or if it was related to the presence or absence of resilience in these youth. Luthar, et al., (2000) in their appraisal of the resilience construct, also spoke to the weaknesses of the model and the methods by which researchers have attempted to tease out the elements of resiliency. Thus, it is important to note that the work is still evolving, and that the operationalization and evaluation of resilience theory must be responsive to the social context in which a target group lives.

Locus of Control

One measure of psychosocial functioning in childhood is determining by perceived locus of control. Locus of control derives from the social learning theory of Rotter (1966), and centers on expectancies for the future rather than as an explanation of past outcomes. In 1979, Rothbaum, Wolfer and Visitainer described locus of control as the perception and "attribution of causality to internal or external factors" (p. 118). A person with an external locus of control perceives their life as under the influence of

powerful others, which makes life unpredictable and unknowable (Rotter, 1966). Those with internal locus of control believe that they can determine their actions and course of their own lives, characteristics that are embedded in their basic personality structure (Rotter, 1966). The theory postulated a uni-dimensional bipolar factor for prediction of behavioral outcomes (Klockars & Varnum, 1975). Kleiber, Veldman, and Menaker (1973) joined others in stating that the scale has some utility, but they have criticized the predictive ability of the scale, and supported its use only for global description.

Utilizing the basic locus of control construct, Rothbaum, et al. (1979) investigated behavioral outcomes as correlated to locus of control with 4- 12 year old children utilizing the Nowicki-Strickland as well as other instruments. The children with higher perceived external locus of control exhibited more internalized coping mechanisms than those with perceived internal locus of control. This finding, among many, corroborated the theory that there is a relationship between a child's perception of control/lack of control of their world and how they then cope with the perception (Rothbaum, et al., 1979). Some years later, Furnham and Steele (1993) performed a thorough review of locus of control questionnaires including those specifically geared toward children. Problem solving approach and goal orientation were the most highly correlated indicators of internality/externality across several instruments (Furnham & Steele, 1993).

Since this study was intended to be a foundation for looking at the future needs and integration of HIV positive AIDS orphans into Tanzanian society, Murasko's (2007) assertion, that because locus of control and self esteem perceptions in childhood may be predictive of needs and support necessary for adolescents, is important to consider. He

particularly highlighted this correlation in the realms of young adult health and educational attainment, two of the major areas of concern in this the target group (Murasko, 2007).

As with other concepts discusses above, questions arise about the cross-cultural validity in locus of control scales. In fact, the concepts of internality and externality are in some cases related to cultural values for each. Thus, one of the problems in using the existing analyses of this trait is the reliance on correlations found in Western value systems (Furnham, et al., 1993). Smith, Trompenaars, and Dugan (1995) attempted to ascertain the cross-cultural validity of the Rotter Locus of Control Scale by administering the instrument to over 9,000 adults in 43 countries. They identified disparate results between countries where individualism or collectivism was most valued, and societies where there was a strong belief/disbelief in the role of luck in future outcomes (Smith, et al., 1995). That being said, the concept was still found to be useful in describing relationships between locus of control perceptions and other areas of psychosocial functioning (Smith, et al., 1995). An early test of the instrument in South Africa revealed that, although there was variability in the results between 15-21 year olds based upon socio-economic status, sex, and age, using the results as a global concept provided some clues to the young people's expectations for the future (Riordan, 1981). Wood and Hillman (1996) had similar results in their study of 117 disadvantaged African American adolescents. The consensus in these studies and others was that general patterns can be elucidated from the findings, but their highest use is as a descriptive, rather than predictive, measure (Rossier, Rigozzi, & Berthoud, 2002). Since the scope of this study is

descriptive, locus of control theory was utilized to provide information about the subjects' perceptions embedded within their social milieu.

Sense of Coherence

In 1978, Antonovsky developed a construct he called *sense of coherence* (SOC), which postulated that persons who can develop this particular global orientation to handling stress will fare better, and report better quality of life, when confronted with life situations than those who are without this orientation (Ericksson & Lindstrom, 2007). Smith and Meyers (1997) called sense of coherence "a stable dispositional orientation [in which] previous successful problem solving leads a person to believe that future problems will be equally solvable" (p. 514). Also called salutogenesis by Antonovsky (1993), the concept is comprised of three factors: comprehensibility, manageability, and meaningfulness (Lustig, Rosenthal, Strauser, & Haynes, 2000, p. 134). Comprehensibility is present in those who view the world as a predictable place, where order can be expected and events can be explained (Lustig, et al., 2000).The factors that comprise manageability are an individual's belief that they have the personal qualities and abilities to manage any situation, or confidence that necessary support is available through their social network (Lustig, et al., 2000). Meaningfulness, in this construct, is the belief that challenges are worth the investment of time, attention, and commitment to work them through (Lustig, et al., 2000). Lustig, et al. (2000) express the view that meaningfulness is the most important of the factors, since it provides the person with the reason to engage in comprehending and managing the crisis.

Sense of coherence is a collection of beliefs and skills that derive from a pattern of positive experiences with the world over time. Antonovsky called one group of life conditions that can presuppose to development of sense of coherence "generalized resistance sources", comprised of such things as religious faith, sufficient economic resources, and social support (Antonovsky, 1979). It is from this set of circumstances that consistency, the basis for comprehension of the world, and belief in the existence of resources, the source of manageability, can provide the conditions necessary for development of sense of coherence. With this set of beliefs a major life stressor can be interpreted as a challenge rather than an insurmountable problem. SOC is closely related to other theories such as will to meaning, locus of control, learned helplessness, and resilience that attempt to describe differential responses to stress (Bowman, 1996).

Sense of coherence theory has been widely studied in groups experiencing a variety of stressors, but less frequently in disabled populations or those with chronic illness (Lustig, et al., 2000). In addition, Bowman (1996) introduced the observation that persons who function with high levels of pain or serious health problems may have difficulty finding meaning in the health condition, and manageability may be thereby eroded. Antonovsky stated that although sense of coherence can remain fairly consistent over the lifespan, major changes in life circumstances, such as a chronic illness crisis, can have a profound effect upon SOC (Antonovsky (1993) in Bowman, 1996). Further research is necessary to investigate the utility of sense of coherence theory in regard to management of chronic illness or disability.

Very little was found in the literature regarding theoretical applications of sense of coherence theory in children, perhaps because of the necessity of a cumulative accumulation of positive interactions with the environment that contribute to the development of the coherent world view. Sense of coherence has been demonstrated to develop increasingly throughout childhood, adolescence, and then into adulthood. Hakanen, Feldt, and Leskinen (2007) reviewed a 13 year longitudinal investigation of the stability of high SOC to support the contention that time is a necessary factor in development of SOC. The study followed participants from adolescence into adulthood. In other studies, the longitudinal experience of the previously described resistance sources such as faith and economic security, throughout childhood was pivotal to development of high SOC later in life (Kivamaki, Feldt, Vahera, et al., 2000; Suominen, Helenius, & Bloomberg, 1999). No usage of sense of coherence theory with children younger than 12 years was found in the literature (Honkinen, Suominen, Rautava, Hakanen, & Kalimo, 2006). Thus, although an important consideration in investigation of coping mechanisms in high stress situations, sense of coherence theory is not useful in the description of the experience of young children living with chronic illness.

Learned Resourcefulness Theory

Rosenbaum's theory of learned resourcefulness emerged from Bandura's (1977, 1980) theory of self-efficacy. Although conceptually linked, learned resourcefulness postulates that cognitive strategies useful in dealing with future stressful events can be developed by an individual from the learning that occurs as a result of current

experiences (Bandura 1977; Rosenbaum, 1990). Folkman provided additional description of the process, as "reducing, minimizing, mastering, or tolerating the internal and external demands of the person-environment transaction that is appraised as taxing or exceeding the person's resources" (1986b, p. 572). Learned resourcefulness, then, is a predictor of self-efficacy in the future that is triggered by and developed in a particular stressful experience, what Bandura called the enactive mastery experience. (Bandura (1997) in Bilgin & Akkapulu, 2007). The Rosenbaum Scale measures the extent to which a person can make use of cognitive strategies when under stress in the future (Rosenbaum, 1990).

Akgun (2004) explored these concepts, and found that persons who are high in learned resourcefulness actually cognitively minimize the negative effects of stressful situations rather than developing coping mechanisms for the negative effects. He stated that learned resourcefulness allows the individual to self-regulate and mitigate that which gets in the way of self-efficacy and what he calls "planful problem solving" (Akgun, 2004, p. 445). In addition, Akgun (2004) found that persons with low learned resourcefulness often utilize avoidance as their approach to stressful conditions. The source of learned resourcefulness in adolescents was illustrated by the study of Thai children 12-17 years old with asthma (Preechawong, et al., 2007). Where one might expect that strong family support would contribute to the development of the ability to cope with future asthma-related stressors, these researchers found that, after controlling for gender and age, only 10.6% of resourceful coping derived from healthy family functioning and support (Preechawong, et al., 2007). Another surprising finding was that

only 3.3% of the resourceful coping could be correlated to high measured levels of self esteem (Preechawong et al., 2007). The authors believed that these findings support learned resourcefulness as a separate process developed by the individual that is not correlated to relationships with others or even with other measures of self concept (Preechawong, et al, 2007).

Panitrat and Zausniewski's (2001) earlier study with 281 Thai youth measured learned resourcefulness in its relationship to amphetamine use. They found an inverse relationship between the two factors, i.e., those with low learned resourcefulness scores manifested high amphetamine use to mitigate stress and vice versa (Panitrat and Zausniewski, 2001). The predictive rate of the correlation in this sample was 83% (Panitrat and Zausnieski, 2001). Ness and Macaskill (2003) explained this type of correlation as demonstration that persons with high learned resourcefulness do not rely on coping strategies for managing anxiety, but in fact utilize cognitive problem solving instead.

Instruments to Assess Quality of Life

A variety of instruments have been developed that provide some clues to successful emotional functioning in children. For example, Spencer (2006) examined the utility of KIDSCREEN™ to test a hypothesized correlation between children's health-related quality of life and socioeconomic background. Some patterns related to parental level of education and financial status were observed, particularly in adolescents (Spencer, 2006). Earlier in this review the study by Young, utilizing KIDSCREEN-28™ to assess quality of life in disabled children, revealed participant- described contributing

factors not assessed by the instrument (Young, et al., 2007). More complete results were obtained in Gkoltsiou, Papaevanelou, Constantopoulos's (2008) test of the PEDSQL version that had been developed for use with Greek children. Thus, the cross-group validity of the PEDSQL was found to be better than that of the KIDSCREEN-52, even though both instruments were designed to measure childhood quality of life.

There is often concern with the validity of instruments across cultures. Schmidt and Power (2006) assessed this issue with the DISABKIDS quality of life battery for disabled children in a cohort of 1153 children living in 7 European countries. The investigation revealed some disparities in the socio-emotional dimensions between countries and variability between gender and age that necessitated some adjustments in the analysis of covariance validity (Schmidt & Power, 2006). In 2003, Rosseli and Ardilia discussed the cultural and educational effects upon various non-verbal types of tests, and the danger of drawing conclusions from the findings without consideration of these effects (Rosseli & Ardilia, 2003).

Another consideration in validity issues of instruments is considered in Robitail, Simeoni, Ravens-Sieberer, Bruil, & Auquier's (2007) analysis of the difference in reports between child proxies and the children themselves. This group also used the KIDSREEN-52, and found that the agreement/disagreement between the 2 groups of reports differed by country, gender, and age (Robitail, et al., 2007). Highest levels of agreement were found in physical and cognitive functioning, while social and psychological domains were areas with the highest level of discrepancy (2007).

Methodology and Methods

Van Manen (1990) stated that the methods employed in any research must be derived from the methodology that underpins the investigation. This view is echoed by Kvale (1996), who reminded us that methodology provides the fundamental philosophical view that guides the method. Gadamer (1975), in *Truth and Method*, described the use of objective investigation as antithetical to the goal of the social sciences. He supported the Husserlian (1970) view that these investigations forced human science to become alienated from human experience (Gadamer, 1975). Van Kaam (1966) proposed that quantitative or theory- based research designs may result in the collection of data that distorts, rather than discloses, the lifeworld of the participant, description of which is the goal of research about the human experience (1966).

Rubin and Rubin (1995) joined others in supporting the use of qualitative research methodology for inquiries that require flexibility and iterative information gathering rather than hypothesis testing or theoretical modeling. Within the scope of qualitative methodologies, phenomenology provides the framework for a priori description of the meaning of a particular human experience. Husserl (1970) and Creswell (2003) defined phenomenology as a science that deals in descriptive psychology, naturally lending itself to naturalistic data collection. Alfred Schultz (1967) supported this point, noting that phenomenology does not seek to learn about a situation from the outside, but from the point of view of those who experience it and how they make sense of it. Schultz (1967) believed that the phenomenological researcher has implicitly stated his/her methodological position; that the "world is one of intersubjectively constructed

meanings", and that the methods for gathering the data that will elucidate these meanings must naturally derive from the underlying fundamentals of this belief (p.106).

Interviews and Narratives

Schultz (1967) supported the use of narrative accounts and extended interviews as tools for understanding the life world of the individual. Narratives provide a window into the individual process of a person, since cultural meaning, point of view, and psychological barriers are revealed in the telling of a story (Mattingly & Lawlor, 2000). Blumenreich (2004), in his research with HIV infected children, joined Jacques Derrida in a poststructuralist analysis of the usefulness of the narrative. Blumenreich supports the view that the narrative is inherently an incomplete picture of the phenomenon under investigation, and other methods should be used to supplement narrative-derived information (Blumenreich, 2004).

The interview is one such method, which has been increasingly used in social science research (Mattingly & Lawlor, 2000). Kvale (1996) suggested that there are seven stages of the interview process: thematizing, designing, interviewing, transcribing, analyzing, verifying, and reporting. Bruner (1990) and others believed that the interview and the collection of narrative are particularly useful in understanding the lived experience of those with disabilities or chronic illness (Sacks, 1987, 1995; Frank, 1999; Kleinman,, 1988; Luria, 1972).

Phenomenological Methods in Interviewing

Although the narrative and interview are commonly used procedures in qualitative inquiry, they have a specific form when utilized in phenomenology (Van Manen, 1990;

Moustakis, 1994). Phenomenological interviewing can be the entry into deeper understanding of the human phenomenon of interest. Moustakis (1994) supported Descartes (1912), saying that he wished to access the "knowledge that comes from self-evidence" (p. 44). Verbal report is the best data collection device for obtaining this knowledge, what has been called "thick description" of the lifeworld of the participant (Mattingly & Lawlor, 2000, p. 5). Dilthey's (1987) view of the data collection process was one designed to elicit the first hand report of thoughts, emotions, and memories regarding the phenomenon as experienced. Creswell believed that self-report of those who have experienced a particular phenomenon is the key to deriving, as Moustakis (2003) said, "the essences of the structures of the experience".

Phenomenological interviews elicit the participant's account of their experience of the self in the world, and indeed, in their own body (Van Manen, 1990). Moustakis said that these interviews are not intended to predict causal relationships (1994). Bruner (1990) added that the personal narrative illuminates motives and context for how the individual acts as they do, including the restraints that preclude certain types of action. The questions developed for this purpose provided deeply rendered pictures, instead of measurement, of the experience (Moustakis, (1994). In addition, the questions provided only a guide for the interviews, since they were designed to be used out of sequence, altered during the interview process, or even omitted if the purpose of description of the lived experience was best served by these adjustments (Moustakis, 1994). Early phenomenologists Husserl (1970), Heidegger (1962), and Dilthey (1987), described the importance of bracketing, or epoche*,* the setting aside of preconceived ideas the

researcher may have about the participant or their experience. Van Manen (1990), supporting bracketing technique, believing that the phenomenological interview is useful in meeting people primally, without preconception or interpretation, as a means to elucidating their authentic experience.

One of the products of the interview process is the elucidation of localized meanings for concepts such as anger, pain, or suffering (Wetherell & Maybin , 1996). It is during the interview process that the researcher is able to garner sufficient information to develop such concepts in the cultural and local social context (Schenk, et al., 2008). Once these concepts are well described, the narratives become more useful to the researcher (Schenk, et al., 2008). Another consideration, specifically when the language of the interview and the language of the analysis are not the same, is concern for the meaning of concepts in each of the two languages (Temple, 2008). Awareness of this problem, and development of processes in data collection, transcription, translation, and analysis, help to mitigate the possible misinterpretation of raw data from which findings are developed (Temple, 2008).

Interview and Other Techniques with Children

Children have been increasingly viewed as independent and competent social actors in their own right, from whom important information about their environment may be gleaned (Barker & Weller, 2003). The United Nations Convention on the Rights of the Child upholds the dignity of children by supporting their right to speak on any matter that affects them (Morrison, Moir, & Kwansa, 2000). Evidenced- based support for use of one data collection method over another with children, however, was still sparse (Myfanwy,

Gibbs, Maxwell, & Britten, 2002). When eliciting experiential information from children, a varied set of activities, as well as use of a child- friendly space, may be useful (Myfanwy, Gibbs, Maxwell, & Britten, 2002). Asking a child to share their experience of a particular event in anecdotal form often is a successful way to generate narrative data (Van Manen, 1990). Many children enjoy painting or drawing while talking about their lives, and the activities create ease and support unselfconscious disclosure of revelatory information (Van Manen, 1990; Darbyshire, et al., 2005). Hemming (2008) supported the utility of mixed techniques that are child centered in addition to semi-structured interviews, to mitigate the impact of the short attention span of some children as well as the possibility of resistance to certain lines of questioning. A naturalistic approach supports the needs of broad, exploratory research (Morrison, Moir, Kwansa, 2000). Using several techniques with children can provide additional and complementary information that make narrative and other forms of oral report more clear (Darbyshire, MacDougall, & Schiller, 2005).

Value may be added to the data collected from children through the use of a variety of interactional methods, but care must be taken to minimize the scope of the investigation across techniques (Darbyshire, et al, 2005). Instruments that use pictures, such as those used for child self report of pain intensity, have been demonstrated to be useful in eliminating barriers to comprehension or to transcend the limitations of language facility often present in young children (Spagrud, Piira, & von Baeyer, 2003). Cross- cultural use of such batteries with children must be carefully considered, however, as concepts that are culturally linked might be misinterpreted by the participant, the

analyst, or both (Beckstead, Yang, & Lengacher, et al. 2008). Beckstead, Yang and Lengacher (2008) recommended item analysis before inclusion as the only way to ensure language and meaning congruence.

Important conditions differentiate the way researchers collect qualitative data from adults and how they collect data from children. First, we must realize that different information and attitudes exist about the same experience of interest between children and their caretakers. They are equally valid, but come from different points of view (Morrison, Moir, & Kwansa, 2000). Secondly, the researcher must adopt a respectful attitude that does not support power inequity between the adult researcher and the child participant. This concern extends to consent/assent agreements, which must be executed in such a way as there is no coercion present in the interaction (Morrison, et. al, 2000). Thirdly, the cultural imperatives of adult-child interactions, as well as culturally or socially accepted ways of expressing feelings, must guide the meetings and be part of interviewer preparation (Morrison, Moir, & Kwansa, 2000).

Summary

The quality of life of Tanzanian children who are AIDS orphans infected with HIV/AIDS is determined by the physical manifestations of their disease, the emotional stressors attendant to the disease and orphanhood, and the children's ability to function within their society. The complex interplay of these factors is the lived experience of these children. To date, extensive research has been done about each of these factors in isolation, although much of it was performed in other countries or on other continents. However, little effort has been made to create a unified picture of the phenomenon,

particularly from the children's point of view, in Sub-Saharan Africa, and Tanzania in particular. This investigation provided such a description, adding to the body of knowledge necessary to support the children and the societies in which they live. Chapter 3 will describe the research method and protocols. Data report and interpretation will be provided in chapters four and five. Chapter five also will include recommendations for action, areas in need of further study, and the social change significance of the results to individual Tanzanians, as well as Tanzanian society at large.

CHAPTER 3:

RESEARCH METHOD

Research has been performed that describes the life circumstances of African AIDS orphans and other vulnerable children. In addition, the experiences of adults infected with HIV have received attention, both locally and globally. Although many in the field are beginning to recognize the scope of the pediatric HIV epidemic, few have begun the ground work of description of the phenomenon. This study will begin that process within the Tanzanian context. Chapter 3 explores the philosophical base that guided the methods of the study, selection criteria and processes for participants, description of data to be collected, format for data collection and analysis, as well as the role of the researcher in all of these activities. This research was performed under Walden University IRB approval number 02-11-09-0309570.

Research Question

What are the qualities of the physical, intellectual, emotional and social experience of living as an HIV-infected Tanzanian orphan?

Sub questions

1. How do HIV-infected Tanzanian orphans think they compare to other children (a) physically, (b) intellectually, (c) emotionally and (d) socially?
2. How do HIV-infected Tanzanian orphans perceive what the society is telling them about their identification as orphans infected with HIV?
3. What factors are present that support these children in coping with both orphanhood and positive HIV status?

4. How do these children rate on standardized quality of life indicators?
5. How do HIV-infected Tanzanian orphans living in institutional settings compare on the above four parameters to similarly-described children living in village settings?

This researcher recognized the possibility of other questions emerging during the data collection phase which might contribute to understanding of the phenomenon of interest.

Research Design

Rationale for Phenomenology

The purpose of this investigation is description of the life world of the HIV positive Tanzanian orphan. A qualitative approach was, therefore, the most appropriate form of data collection, since this researcher did not seek to measure but simply create a picture of the experience from which its meaning can be extracted. Creswell (1998) delineated the criteria for measurement of a well executed naturalistic study. Among the components that are of particular importance to this inquiry are the depth, breadth, and care taken with data collection, extensive time in the field, evolving design, and attention to the multiple realities that are expressed within naturalistic research (Creswell, 1998). Dilthey (1976) asserted that the world of the human is characterized by conscious experience, which is, by its nature, subjective. He suggested that nature can be explained, but people must be understood (Dilthey, 1976). Of the qualitative traditions, phenomenology provided the approach to lived experience that was best suited to the scope of this investigation.

Phenomenology recognizes the importance of first person perception to developing a description of the essence of a phenomenon. The reality and meaning of a particular human condition can only be described by those who are consciously experiencing it (Creswell, 2003). The first person interview is the best method for collection of the information that will lead to a construct of meaning. Per William Dilthey's (1976) description of the data collected by phenomenologists, this researcher elicited first hand report of the "thoughts, consciousness, values, feelings, emotions, actions" and memories of the subjects' experience of their world and this phenomenon (Moustakis, 1994, p.34).

Other forms of qualitative inquiry might have served some purposes of this inquiry. Because no attempt was made to locate the phenomenon within a social construct, as might be sought in an ethnographic study, and, although a case study or biography could have provided some clues to the experience at issue, a sample of more than one individual offered a larger set of reported experiences to guide the effort to distill a more valid meaning of the phenomenon beyond a single child (Creswell, 2003).

Phenomenology

Description of the nature of the experience of HIV positive orphanhood was well served by phenomenological investigation. Gubruim and Holstein (1997) proposed that the best way to conduct human research is not by using analytic approaches or cultural or other preconceptions about a phenomenon being studied, but to approach it from a naturalistic point of view that allows for unbiased report from those experiencing it. Van Kamm (1969) warned that standard scientific experimental design is not well suited to

human research, as conclusions based upon numerical calculations cannot fully describe the "multiple interwoven layers of the human experience"(Van Kamm, 1969, in Moustakis, p. 45). He was concerned that the restrictions imposed by theoretical constructs or experimental designs would distort, rather than explicate, the raw data of human experience. This approach echoed Husserl (1931), who emphasized the importance of learning from others by identifying with their individual reality rather than performing controlled experiments. In the phenomenological inquiry, information is gathered at the pre-reflective, pre-theoretical level. Phenomenology acknowledges that subjective experience, or even imagined events, still are quite real to the human subject, and therefore constitute a source for understanding.

Babbie (2007) said that the phenomenologist's job is to make sense of the way people experience a human condition. Van Manen (1990) further explicated this idea, suggesting that we hunger to make sense of the life world of persons experiencing a phenomenon, in order that we might understand. He described phenomenology as a philosophy that embraces the idea that any event or circumstance may be experienced in a unique way by each individual, yet we can still extract more universal meanings from these experiences (Van Manen, 1990). Merleau-Ponty (1962) described phenomenology as an approach that searches for what it means to be human. It is this information which Husserl (1970) later suggested is the basis for identifying clusters of meaning that lead to a conceptualization of a particular phenomenon as experienced.

Phenomenologists approach investigation of the human condition in several distinctly different ways. The differences between two of the most widely used

approaches, empirical phenomenological investigation and heuristic phenomenology, lie in the goals of each (Moustakis, 1994). Empirical phenomenology seeks a transcendent description, while heuristic inquiry attempts changes in perception of the researcher regarding the phenomenon (Moustakis, 1994). Creswell (2003) believed self report of individuals who have experienced a particular phenomenon is the key to deriving, as Moustakis said, "the essences of the structures of the experience" (Moustakis, 1994, p. 13). Recognizing that researcher reflection is an essential part of the data analysis process in phenomenological inquiry, I expected to learn and change as I performed this investigation. However, the heuristic goal of self discovery was not a primary consideration. Kant (1966) asserted the belief that *a priori* sources provide the transcendent description that I sought regarding the meaning of the human experience of HIV positive orphanhood in Tanzania that is a necessary first step in developing approaches to assist those experiencing the phenomena.

Epoche or bracketing. One of the essential features of phenomenological research is the suspension of interviewer bias or agenda. As Field and Morse (1985) noted, the phenomenological researcher arrives at the data with all preconception about the phenomenon set aside, or bracketed, allowing the data to guide the direction of the analysis to recognition of patterns and themes. This approach is based upon the Greek principle of *epoche,* delineated by Descarte (1912) and Husserl (1931), that demands the suspension of supposition or pre-judgment as a necessary first step in description of the human condition. This basic precept of phenomenological research will be revisited in the data collection and analysis sections that follow.

Research Participants

In order to honor confidentiality agreements with the participants of this study pseudonyms have been used for both organizations and individuals participating in this research.

Rationale for Participant Inclusion

Phenomenological investigation, compared to other forms of qualitative research, is best served by deep inquiry through a series of long interviews with a smaller number of participants (Moustakis, 1994). In this way, sufficient amount and richness of text can be generated from which to derive the sought-after patterns of meaning. The first person interview provides the description of the phenomena from the person who is experiencing it, without filter or aspects that might be lost by secondary report.

Some have questioned the utility and validity of interviewing children directly, rather than using the perceptions of parents, grandparents, or guardians. Support for the utility of children as first person reporters is, however, provided by the children themselves in previous investigations. When Roberts (2005) investigated barriers to children's ARV adherence, he discovered that the children and their caretakers had very different perceptions of the reasons for poor adherence. Brown and Lourie (2000) further supported the importance of first person report by children in their study of self- reported pain and sleeplessness in chronically ill children. And when Young, Rice, Dixon-Woods, Colver and Parkinson used KIDSCREEN™ to determine quality of life in a cohort of children with cerebral palsy, the children reported that the instrument lacked

measurement of experiences they thought were important contributors to description of their quality of life. Based upon these findings, and the central importance of first person report to phenomenological description, I utilized data generated directly from interviews with the children, since it was the child's own experience and perception of the phenomenon that I wished to understand and describe.

Sampling Frame

The population from which participants were recruited for this inquiry were male or female children living in the rural areas that border the highway within 30 km to the east of the city limits of Arusha, Tanzania. The children considered for participation were those between the ages of 9 and 12 years who had laboratory confirmed HIV infection assumed to be perinatally acquired. The age of the children was purposely selected to support the likelihood of infection through perinatal exposure. It was, of course, possible that these children had been infected through sexual contact, but it is much less likely in this age group than might be the case with children over 12 years of age. Additionally, the children selected were aware of their HIV status. Confirmation of the children's knowledge of their HIV status was obtained through the executive director of Holy Cross Nursing Home and Orphanage in the case of children living there. The Orphan Services Coordinator at Arumeru AIDS Outreach, the other community partner, confirmed with the potential participant families that the children recruited from the local villages were aware of their status. These confirmations were acquired prior to recruitment visits. All participants were AIDS orphans, as defined by the researcher as a child who has suffered the death of one or both parents to AIDS.

Sample Description

A purposive sampling method was employed to generate a total sample of 12 children, 6 of each sex, who meet the following additional criteria:

1. Six children (3 girls and 3 boys) who resided at Holy Cross Nursing Home and Orphanage, and
2. Six children (3 girls and 3 boys) who resided with grandparents or guardians in local villages.

The sample size was chosen in an attempt to represent the life world of a variety of children sharing a similar phenomenon. However, this researcher recognized that there may have been a need for flexibility in the field to replace any participants who dropped out and to ensure the generation of sufficient amount and quality of data to complete the analysis.

Access to and Recruitment of Participants

Access to potential subjects living in the villages of Arumeru district was granted by the executive director of Arumeru AIDS Outreach (AAO), an NGO that has identified and works with AIDS-affected and infected orphans in the area. AAO has been working with the surrounding communities for 10 years, providing HIV preventive services and also identifying orphans as well as adults who are living with the effects of HIV/AIDS (WAMATA, 2001). One of the most pervasive effects of the pandemic is the growth in the number of orphans (UNAIDS & UNICEF, 2007). AAO has taken the lead in identifying orphans and vulnerable children in the surrounding villages, and has worked

to provide social and educational services for the families housing orphans (WAMATA, 2001). It has become a place to which families come to solicit help. In recent years AAO personnel have become aware, by disclosure from the guardians, of increasing numbers of orphans who are also infected with HIV, and hope to develop programs to assist (E. Mawere, personal communication, September 18, 2008). Because orphan services personnel are well known in the entire region by sight, orphanhood is the identifier for the children with whom they work, not HIV status. No additional protections were necessary for recruitment among this population, as regular home visits by these personnel, often accompanied by others, to registered orphans usually occurred monthly (M. Muasa, personal communication, May 5, 2007).

The families in this pool of possible participants live in rural villages reached primarily by foot, sometimes at a great distance from the main paved road and AAO and Tanzania Project offices. The residents usually come to this area on the twice weekly market days, and if in need, might stop at the AAO offices before continuing to carry home, manually, food purchased at the market. They may have all the children of the household in tow, or may leave all of the children behind with a neighbor if they are bringing produce to the market to sell. It was the judgment of this researcher that it was near to impossible to ask for these already burdened guardians to come to a meeting to discuss their wish to volunteer for research study participation. Because the culturally accepted AAO staff visits to the home of the identified orphans are already occurring, it was most appropriate to meet with guardians and prospective participants in their homes.

Informed Consent and Assent

Subsequent to consent and assent, the guardians were given their choice of meeting place for the first interview, either at the home, which was chosen to provide comfort to both child and guardian, or an anonymous location. All subsequent interviews occurred out of the home at Tanzania Project offices, for the purposes of both logistics and confidentiality. Private meetings were conducted with each potential participant, their guardian, a member of the orphan services staff, the children's advocate, the indigenous research assistant, and myself. I was present at these meetings to ensure that the proper protocol for obtaining consent and assent was followed. The consent and assent forms were presented in Swahili. Where guardians or children were not sufficiently literate to read the forms, they were read out loud, and I ensured that all the telephone contact information as well as questions and answers were well understood. Following this meeting, the potential participant and their guardian were given 24-48 hours to think about their willingness to participate. At this point the entire group named above returned and both oral and written (or witnessed) consent from the guardian was requested. If the guardian or child were not sufficiently literate to read and understand the forms, the forms were again read out loud and the request and responses giving consent were audio tape recorded as well as witnessed in writing. Following guardian consent, child assent was acquired in the same manner. This process was followed until a sufficient number of child participants had been identified.

Access to potential subjects residing at Holy Cross Nursing Home and Orphanage was granted by the executive director. Holy Cross Nursing Home and Orphanage was one of only 3 orphanages in Tanzania that was willing to care for HIV infected children. The community in which it operates is well aware that all the children residing at Holy Cross are HIV positive or suffering from AIDS, and community leaders are proud that such a facility exists to serve their community. The children themselves learn of their status as soon as they can be expected to understand, around 6 years of age. School teachers and administrators are also aware of the children's HIV status. Because full disclosure is in operation at and around Holy Cross Nursing Home and Orphanage, no additional protections to these children were necessary. In operation since 2004, Holy Cross has become an increasingly important voice in the national dialogue on meeting the needs of these children.

Recruitment of this group of subjects took the form of private meetings that included each potential participant, the executive director, the indigenous research assistant, the child advocate and myself. I was present at these meetings to ensure that the proper protocol for obtaining consent and assent was followed. The consent and assent forms were presented in Swahili. The executive director, as guardian, was known to be literate in both Swahili and English. The potential participants were not sufficiently literate to read the forms, therefore the assent form was read out loud, and I ensured that all the telephone contact information as well as questions and answers are well understood.

Following this meeting, the potential participants were given several days to think about their willingness to be part of the study, and consent from the director, as well as subsequent written and/or oral assent from the child, was requested. The executive director, as guardian, was known to be literate and gave consent in written form. The potential participants were not sufficiently literate to read the forms, so the forms were again read out loud and the request and responses giving assent were audio tape recorded as well as witnessed in writing. This process was followed until a sufficient number of child participants were identified.

This researcher recognized and took steps regarding the possibility that community partners might place their own interests above those of the child participants by voicing these concerns when soliciting the community partnership agreements. Leadership, as well as any staff involved in the recruitment process, were told that the protection of the confidentiality and other needs of the child was my, and must be their, most important concern. Additionally, this researcher verbally reiterated my commitment to the separation of the activities of the organizations from the research protocol, and the complete independence of the research from the financial or other agreements made by the executive board of the Tanzania Project. I was alert to signs that the community partners were putting their own interests first, and was prepared to intervene immediately. I attempted to anticipate any circumstance where the interests of the children were not remaining the highest priority, maintained vigilance in this pursuit, and was prepared to deal with such circumstances as they occurred.

During the recruitment process, the following information was shared with all guardians and potential participants. Confidentiality was assured both by coded assignment of a numeric identifier to each participant and an Arabic letter to each family rather than using actual names. The anonymity of the participants and families was assured by written agreement as part of the release form, and included the lead researcher, research assistants, NGO staff, child advocate, and translator. Special emphasis was placed upon local anonymity, since the community may not know the status of the HIV infected child, and revelation of that information could lead to stigma or other negative impact to the family. To this end, interviews were conducted either in the home or at a safe and anonymous location where secrecy could be well protected. All audio tape recordings were kept in locked storage at Tanzanian offices until their subsequent transfer to US offices for the required 5 years.

Informed consent and assent included description of the scope of questions about the lived experience of the participants that were to be probed during interviews, as well as disclosure that the interviews were to be audio taped. Assurance that compensation was not tied to completion of the interview process, but proportional to the level of completion including transport costs, was given at this time. All information was presented by native speakers in Swahili at a level that was appropriate for potential participants and caretakers. In addition, benefits to the participant, family, and the wider community as well as possible risks to the children and families were candidly discussed, so that all parties were clear about the intent of the research as well as the small possibility of unexpected outcomes (Holloway & Wheeler, 2002). Consent and Assent

Forms appear as Appendix A. As Polit and Hungler (1999) said, consent and assent in this type of research must be viewed and enacted as consensual decision-making, which provides the opportunity for the participant (and/or guardian) to deny permission for continued probes into some areas, and includes an "opt out" for discontinuation of participation without prejudice at any point in the process.

Bhutta (2004) discussed the important considerations of informed consent when performing research in developing nations. He describes a conceptual framework that satisfies all the possible concerns by suggesting the following steps:

1. Sharing of information about the content and intent of the research as well as participant rights with prospective participants in their native language and at a level easily understood by all. Sufficient latitude and time for questions and clarification is given.

2. In depth discussion and interaction between the participants and researchers to make sure the participant clearly understands what is being asked of them, how much time will be involved, and benefits that may accrue as well as researcher responsibilities, until full understanding is attained.

3. Free choice of the participant to accept or reject participation. Informed consent can be given by witnessed verbal agreement if the participant is illiterate and therefore unable to affirm in writing. Previous translation and back translation of the informed consent document language to be read or affirmed orally will reiterate that full disclosure and understanding has been attained by the parties (p. 772).

Because of the differential living conditions of the two sources of potential participants, children and guardians living in the villages were offered compensation for their time, including any transport costs for the participant and family. Participants living at Holy Cross Nursing Home and Orphanage received a t shirt. Such compensation was provided proportional to the participant's level of completion of the research activities.

This was within the culturally accepted norms not only for visitation to a local home, but also an expectation of the low income Tanzanian population when asked for their participation in meetings or research of any kind. The letter supporting the research by Child Advocate Ndosi (Appendix A) reaffirms this necessary and culturally appropriate component of recruitment for participation in the study. The children who participated from both settings received snacks and art supplies during the course of the interviews.

Another set of topics that were discussed in the recruitment interviews included the scope of the questions that may be asked of the children. Research staff acknowledged that some of the questions could engender sadness or other difficult emotions, and informed all guardians and children that counseling would be available free of charge to those children or families who might feel the need for such services as a result of the interview process.

Discussions with local stakeholders have revealed that many of these families and children are eager to tell their stories, yet are afraid of the future impact of public revelation upon their lives. Health workers, guardians, and the children themselves decry the lack of services available for HIV positive Tanzanian children, and have informally suggested that the scope of the research may support advocacy for such services or programs. Assurances of confidentiality support positive relationships with both children and guardians, and helped to ensure open communication between participants and interviewers.

Ethical Protection of Participants

Much of the literature regarding the ethics of utilization of children in research concerns their participation in clinical medical research. Helseth and Slettebo (2004) reminded us, however, that the Declaration of Helsinki supports the importance of children's point of view about their life situation to be equally valuable as that of adults. The caveat is that eliciting the point of view of children requires careful protections due to their identification as a vulnerable population. Yet such vulnerability has not been well defined, nor have defined responsibilities toward this group other than parental consent been well described, neither by the Helsinki Declaration nor by the U. S. Office of Human Research Protections Guidebook. The Council for International Organizations of Medical Sciences has, however, paid particular attention to this matter in clinical research in developing countries. In 2002, the Council for International Organizations of Medical Sciences (CIOMS) defined vulnerable populations as: "those who are relatively (or absolutely) incapable of protecting their own interests because they may have insufficient power, intelligence, education, resources, strength, or other needed attributes to protect their own interests" (CIOMS, 2004, section 7). In other literature, the primary concern seemed to be the potential for exploitation of the vulnerable group, in this case children, by the researchers or the research process (Consortium to Examine Clinical Research Ethics, 2004). As evidenced by the elaborate informed consent process utilized in this project, great care was taken in the preparation for conduct of this investigation into the lived experience of HIV infected Tanzanian orphans to ensure that no power imbalance that might lead to exploitation was likely to occur either in the solicitation of participants

or during the interview processes. The lengthy and in-depth informed consent and assent process prepared children and their guardians to engage without fear.

The training, background, and professionalism of the interviewer ensured that great care was used in all interactions with the children. The research assistant was college educated, had received training over the last 3 years from SAT, the Canadian Government's CEDA funded South African AIDS Trust, in issues surrounding HIV/AIDS and children, and was working with vulnerable children. The research assistant was trained that (1) her role was not to provide psychological support or guidance, and that (2) any disclosed abuse, distress or other untoward event was to be reported following the defined protocol to the head researcher for intervention or report to the appropriate authorities.Training of the research assistant included the following topics:

1. Overview of Child Development
2. UN Convention on the Rights of the Child
3. African Charter on the Rights and Welfare of the Child
4. Facilitation and Communication Skills
5. Mock Interviews
6. Protocol for Handling Participant Distress
7. Protocol for Handling Abuse Disclosure

and was co-taught by the head researcher and an indigenous member of the faculty of the certificate program in Children's Rights Advocacy at MS Training Center for

Development Cooperation, a Danish degree granting institution in Tanzania. The Training Guide is attached as Appendix B.

Balen et al (20060 reported that some in the research community decry the disenfranchisement of children when their voice and point of view is silenced by ethical protection rules designed to protect them. This group expressed their concern that protection of children from speaking about their life world can manifest in overprotection and violation of their rights (Balen, et al., 2006). In addition, several authors supported the belief that children above 7 years of age do in fact have sufficient cognitive skill to actively engage in informed consent processes if given developmentally appropriate information and the ability to ask questions (Broome, 1999; Ondrusek, Abramovitch, Pencharz, & Koren, 1998, Shevell, 2002). Participation in discussions about their experiences can be quite empowering to young people as well as lead to greater understanding of their own lives and place in the world. With appropriate informed consent and data collection processes, the information children can share is rich, worthy of investigation, safe, and can lead to important adult support, societal policy change, and advocacy. The proposed investigation was conducted with these concerns, and their mitigation, in mind as well as design.

The confidentiality requirements for participants were provided by coded assignment of numbers and letters to the participants and families rather than actual names. The consent form also contained written confidentiality assurances from the interviewers, translator, NGO staff, and this head researcher. All data were stored in a locked file cabinet in the Tanzania Project office in Patandi, Tanzania during the

collection period, and subsequently in the Tanzania Project office in Santa Fe, New Mexico, USA.

Informed consent and assent included (a) description of the scope of questions about the lived experience of the participants that were probed during interviews, (b) that the interviews were to be completed over a period of about 2 weeks, as well as (c) disclosure that the interviews were to be audio taped. This information was presented by native speakers at a level that was appropriate for sotensible participants and caretakers. The concepts of research as opposed to treatment, as well as volunteerism, were explained. In addition, benefits to the participant, family, and the wider community as well as possible risks to the children and families were candidly discussed so that all parties were clear about the intent of the research as well as the small possibility of unexpected outcomes (Holloway & Wheeler, 2002). Negative reactions were acknowledged as an occasional natural side effect of the interview process that is central to phenomenological research, as emotions or memories that may be uncomfortable for the participant are sometimes inadvertently uncovered (Smith, 1992). On the other hand, these occurrences can be opportunities to explore some of the emotions in a safe and supportive environment- a positive byproduct of participation. Polit and Hungler (1999) said that consent and assent in this type of research must be viewed and enacted as consensual decision-making, which provides the opportunity for the participant (and/or guardian) to deny permission for continued probes into some areas, and includes an opt out for discontinuation of participation without prejudice at any point in the process.

There were a number of additional ethical considerations attendant to the phenomenological inquiry into sensitive subject matter as well as the age of these research participants. Fielding and Thomas (2001) discussed the ethical considerations of the typical interview used for phenomenological inquiry into sensitive subject areas. They were joined by Smith (1992) in their belief that ethical interviewing was within the control and prevue of the interviewer himself. In this study, the well prepared and experienced interviewer applied a sensitive approach to the interview that was watchful of the emotional impact of the deeply self-revelatory process and provided appropriate breaks or other strategies for diffusing discomfort as well as access to follow up support if necessary (Kavanagh and Ayers, 1998). Other risks to the participants from unintentional disclosure of sensitive information or incidental observation of the research process by others were also acknowledged. In addition, we followed the advice of Coyle and Wright (1996) who stated that it is ethically necessary for the phenomenological researcher to be prepared to deal with the impact of the stress of the interviews by providing access to trained counselors for participants or guardians who expresses a need for help in dealing with such problems.

Data Collection

A series of one on one audio tape recorded structured interviews and meetings with each participant were used to collect data. An interview guide supported the interviewer in directing the conversations to the area of inquiry while allowing sufficient open-endedness for the participants to answer in their own way. Use of the interview guide offered the benefits of efficient use of time and consistency of response that

enabled productive data analysis. The interview guide covered all questions that might possibly be asked, but it was expected that not all questions from this collection would be utilized, since the interviewer was required to remain responsive to the flow of the interactions. The order in which topics and questions were presented was flexible. Subsequent probes and follow up questions were used for elucidation of the answers. Some follow up emerged naturally during the course of the interviews rather than appearing in the interview guide. Some new questions emerged from the conversations that also necessitated responsive probes. Because the interview guide was very specific, no advanced administration training was necessary for the research assistant,whose role was to ask questions and properly audio record the responses in a comfortable atmosphere. Mock interview rehearsal was part of the training protocol. The head researcher was present at both interviews with each participant, to ensure that the research processes as approved by the Internal Review Board were executed properly. The interview guide and additional data collection protocols may be found as Appendix C.

The number and length of the interviews was determined by both the observed limitation of each participant and the ability of the indigenous research assistant to obtain sufficient data to support analysis aimed at answering the research questions. It was expected that, on average, 2-3 meetings of approximately 1 hour each would fulfill these requirements. The meetings took place either in the participant's home or a neutral site such as an office in an anonymous location. Guardians were given their choice of home or an anonymous site as the meeting place for the first interview.

Participants were provided with breaks and snacks at appropriate intervals. After completion of the drawing tasks, the participants were allowed to take art supplies home. Because child abuse or neglect are considered criminal acts, the research assistant was well trained on how to handle such revelations at the time that they were made, as well as the protocol for report to the authorities. Compensation for time spent, as well as transportation cost reimbursement, was given to each participant at the completion of the interview process. Guardians were told that if children were withdrawn from the study for any reason they would still receive proportional benefits at the end of the data collection period.

Cross Cultural and Other Validity Issues

Because this project was a qualitative descriptive piece of work, culture-specific rather than cross-cultural validity was the goal. The questions in the interview guide were developed by the researcher to be used in Swahili translation, for both word and concept validity. The Faces Pain Scale, which is the only instrument that was used in this investigation, is a non-verbal facial identification instrument that has been utilized worldwide, including four African countries, and did not necessitate translation. Swahili versions of the interview questions as well as the consent and assent forms, were prepared by the translator with Kiswahili language confirmation provided by a certified language trainer from MS Center for Development Cooperation, which also offers language courses for foreigners working in the NGO sector. Participants subsequently responded to the questions as posed in Kiswahili with the conceptual congruence obtained through the back translation process. The analysis of the data was not intended

to include the cultural or social context in which it occurs, but, in fact to use the phenomenological approach called “bracketing”, without context or preconception of any kind, including language (Gubrium & Holstein, 1997). Empirical phenomenology, as defined by Moustakis (1994), seeks a transcendent description of the phenomenon.

Extensive conversations between this researcher and the translator ensured that the translator understood:

1. The rationale for “bracketing” and how it is necessary to obtain the data in the form that is useable for this methodology,

2. the risk of translation with what the translator thinks the child meant instead of just the exact words they have spoken, including pauses, exclamations, or words that don’t make sense,

3. my concern, as well as my understanding, that he might have his own ideas about what the child is trying to say, but that he must not insert his bias, culture, or knowledge into the translations, and that

4. the head researcher was the only person who would look at the words and find what I was looking for from the raw speech of the children.

Regarding conceptual validity that was be used in data analysis, several Western constructs were used as tools to guide coding, but not measurement. These constructs-- resilience, locus of control, and learned resourcefulness-- had been developed in English, and therefore were best used as analytical guides in English. For instance, locus of

control theory defines personalities as either internal or external, and is prescriptive about the behavior of each type. In the Tanzanian example, internality or externality were assessed only as traits of the participants, and merely to create a picture of the participants' personal responses to HIV positive orphanhood. These constructs only provided initial codes to ensure that analysis provided answers to all of the research questions. Once actual transcripts were available for analysis, new codes naturally derived from the data that provided guidance for in- depth analysis. Again, internal consistency, which was provided by uniformly translated texts and credibility of the reports was the most important factor in creating a culture-specific description of the experience of HIV positive Tanzanian orphanhood.

Some may question the rationale for qualitative data collection in one language, translation of transcripts, and subsequent analysis in a second language. Precedent exists, however, both within the Walden University and the research community at large. The 2002 award winning ethnographic doctoral dissertation by Duffy (2002), HIV/AIDS in Context: The Culture of Health Promotion Among Ndau Women in Rural Zimbabwe, utilized interviews performed and audio taped by a local research assistant in the native language, translated and then analyzed in English, for 8 of the 11 participants. In addition, Ssengonzi (2007) arranged for semi-structured interviews to be conducted in Luganda and Lusoga with Ugandans who care for family members with HIV/AIDS. The interviews were conducted by research staff members who were native speakers. Tapes and other documents were subsequently transcribed and translated into English prior to manual coding and qualitative content analysis. Mzimkulu and Simbayi (2006), in their

investigation of perspectives of African traditional healers on mental illness, had interviews performed and audio tape recorded in the native Xhosa language using native speakers. The recordings were transcribed and translated into English and subsequently analyzed "using thematic content analysis" (p 417). Alazzi (2008) performed an analysis of some of the perceptions of secondary school teachers in Jordan. All interviews were conducted and audio or video taped in Arabic before translation into English and performance of the subsequent qualitative analysis. Thus, this method has been well received as sufficiently reliable in the research community.

Data Analysis

Transcription, Translation, Storage, and Analysis

Data analysis began upon completion of the first interview. Each interview was transcribed from the audio tape recording and translated into English on the translator's laptop computer in Microsoft Word, with subsequent storage on a portable hard drive and generation of a hard copy print to facilitate analysis by the head researcher. All tapes, transcripts, notes, and other materials were stored in a locked cabinet during the data collection and analysis period. At the end of this period the materials will be stored for the required 5 years.

De-identification

De-identification occurred on each tape after completion of each of the interviews. Prior to transcription and translation, the head researcher coded each tape with the identification tag of the participant that was assigned after completion of the

consent/assent process, as well as the date of the interview. The same research assistant conducted all the interview sessions with any one child. Although the identity of the participants was known to the research assistant who was conducting the interviews, they were not privy to the coded ID for the child. No information about the children was exchanged among the members of the research team, nor did the transcriber/translator have access to the identity of the participants.

Bracketing

Because this investigation followed the tenets of phenomenology, all information gleaned, whether from spoken word, drawing, instrument, or interviewer note was approached without preconception or pre-judgment, but only as value-free data. In this way the meaning of the lived experience of HIV positive orphanhood in Tanzania was described through the patterns and themes that developed from the data itself without any bias that would decrease the validity, credibility, or utility of the investigation as a descriptive exercise.

Preliminary Review

Each transcript of a first interview was read to gain an overall sense of the interaction. Participants were assigned identification numbers at this time. Then the transcript was reviewed by this researcher prior to the subsequent interview in order to adjust interview technique, add proposed follow up questions, or address other issues that may have arisen. This process was followed for each interview until the entire data collection process was completed.

Coding

The development of the code book was a creative process, as word choices, grouping of certain words, and descriptive passages provided guidance for development of the description of the meaning of the phenomenon that was the goal of the inductive process of phenomenological research (Moustakis, 1994). As interesting items were noted, they were collected in a document that grew over time. Memos were added in the margins of the text that posed questions, noted ideas or observations, or marked passages to be examined further. This researcher moved between the continually growing coding handbook and the transcripts, keeping in close contact with the raw material, until enough contextual data had been elucidated to begin the process of categorization and pattern recognition. At this point, various methods were used to tease out the relationships between ideas expressed by the participants as well as to define patterns. Frequent conversations between members of the research team were held throughout the data analysis process to fully elucidate the interrelationships between words and concepts expressed by the participants. This information was included in the field notes. The same process was repeated in analysis of the instrument and other data collection techniques used. Finally, a picture of the experience of HIV positive Tanzanian orphanhood was generated based upon the patterns of experience shared by the participants. Because this investigation was descriptive, there was no recognition of any information as discrepant, but instead as contributory to the meaning of the phenomenon, since individual responses to any life condition are expected to be variable.

Sharing Results

One of the primary purposes of this research was to begin the discussion of how best to support the millions of children living in low resource countries who are both orphaned and HIV infected. To that end, sharing the findings of this study with those in both policy and program arenas will be important. The first level of stakeholders with whom the findings were to be shared is leadership of area NGO's, village leaders, and school personnel who work with this population. All of the above will be invited to meetings to discuss the findings and begin to look at local responses to the needs of the children. Special emphasis at these meetings will be upon the organizations that have cooperated in providing access to the participants, as they are in the unique position of being able to develop responses on a small scale that may be replicable in other organizations. In addition, the guardians of the participants could receive, if they wished, a report of the findings about the group but, for reasons of confidentiality, not individual participants including their own. This information will be supplied in a private meeting or written form, as they prefer. It is expected that all of these meetings will all engender further discussions about both individual and community responses.

The next level of persons to receive the findings will be Tanzanian governmental, social, and academic organizations and individuals, since they will be capable of asking additional questions to be explored by future local research. Finally, since Chapter 2 elucidated the need for beginning the conversations on the world stage about these children and the phenomenon that they embody, publication and presentation of the results in academic publications and meetings will support the continuing commitment of

this researcher to the health and well being of Tanzanian, and other, orphaned and HIV infected children.

Summary

Methods used to generate and analyze data that supported this investigation followed the tenets of phenomenological research. The consent procedures, guarantees of anonymity, and secure data handling provided both necessary and sufficient ethical protections for the child participants. Interviews that followed the guide were performed by an experienced and well trained local researcher who adopted an attitude that was devoid of pre judgment or bias toward the information or those who provided it. Data analysis was performed intuitively, with the goal of generating a description of the phenomenon of HIV positive Tanzanian orphanhood. Chapter 4 will provide in depth data findings. Interpretation of these findings, as well as areas for future research, the social change significance of the findings, and recommendations for action comprise chapter 5.

CHAPTER 4:

RESULTS

Introduction

This study explored the life world of Tanzanian children who are both orphaned and HIV positive. I sought to create a phenomenological description of their experience so that individual support as well as tools for integration of this new societal group could be developed. Performing extensive interviews with some research participants who live in village settings and some who live in an orphanage, additional data about the differential experience of each set of children was generated. Chapter 4 describes processes followed during the on-site preparation, data gathering, and data analysis phases of this research. The multiple elements of data tracking constituted an element of the description. A thorough discussion of the findings, presented in relation to the problem and the research questions, will follow. The final section of this chapter is devoted to evidence of the quality of the research as executed. The total time spent in the Arusha and Arumeru Districts of Tanzania was February 1st through March 19th 2009. The actual data gathering was conducted between February 14th and March 8th, 2009.

Preparatory Activities

Upon arrival in Tanzania, I completed a variety of necessary activities before the data generation could occur. On February 2nd, initial meetings were held with the program director and orphan services personnel at the office of Arumeru AIDS Outreach (AAO) to describe the consent and assent processes, the scope of the research, and to discuss the logistical issues of data gathering from the children living in village settings. On February 12th, another meeting with this group, as well as the child advocate and the

research assistants, generated a list of possible research participants from the pool of identified children who fit the research criteria. All members of the above group were native Swahili speakers who were also fluent in English. These meetings were conducted in English. Consent and assent visits to possible research participant families were conducted between February 16-21, 2009. Information about the process was provided to prospective participant families by the native research assistant and orphan services staff in Swahili with ongoing support in English from the head researcher. Out of an identified 10 children who fit the research criteria, consent and assent were acquired from a pool of 7 participants, the 6 required and one additional to be held in abeyance if replacement became necessary. Only one guardian who was approached refused consent for his child to participate in the interview process.

An introductory meeting was held at Holy Cross Nursing Home and Orphanage on February 3rd with the executive director, the counselor, the research assistant who was assigned to conduct the interviews of this group of participants, the head researcher, and the child advocate. At this meeting, full description of the consent/assent process, the scope of the research, and the logistics of data gathering were disclosed and discussed. All members of this group, with the exception of the head researcher, are native Swahili speakers who are also fluent in English. The group identified an initial pool of 8 children who fit the criteria and were living at the orphanage. Initial consent and assent meetings were held with these children on February 12, 2009 and included the executive director, the counselor, the head researcher, the child advocate, and the research assistant privately meeting with each possible participant. Final consent and assent was obtained for and by

participating children, after several days of continued discussion between the children and their counselor, on February 19, 2009.

Several incidents occurred during the consent and assent processes that led to minor changes in the interview protocol. First, at Holy Cross Nursing Home and Orphanage, when the team gave an overview of the content of the interview questions, 2 children independently informed us that they were not orphans, and expected their parents to return to them. Parental death had been verified for all potential participants prior to the meetings, however the research team agreed not to probe this belief, and subsequently changed questions where the word orphan appeared to "children who do not live with their parents" in order to sidestep a very sensitive issue not within the purview of this investigation. Second, because it became apparent that verification of actual age or month of birth of participants was nearly impossible, it was decided not to acquire the weight of the participants, since the purpose of this activity was intended to make a comparison with healthy children of the same age.

Besides preparatory activities related to the participants, the head researcher conducted several activities relating to the research team during this period. On February 6 and 13, 2009 this researcher met with the transcriber/ translator to train him on the issues of phenomenological research affected by the way in which he produced the translated data. In addition to presenting a primer on the process of phenomenological research, and his important part in it, we discussed the logistics of audio tape and document transfer that would ensure confidentiality and smooth transitions. He was

given a Sony M-675V Microcasette-Corder, earphones, and several blank cassettes with which to practice.

On February 4 and 5, 2009, meetings were held between the head researcher and the children's advocacy trainer to develop the training guide for the research assistants. Trainings for the research assistants were held on February 13th and 15th. The training guide is attached as Appendix E**.** Subsequent to the training sessions, one research assistant revealed that he would not be available during the data gathering period. Although a replacement research assistant was identified, it was not necessary to train or use her, since the primary research assistant was able to complete all the interviews with all the participants. This state of affairs added positive value to the reliability of the findings, since all interviews were conducted by a single interviewer.

Data Generation

Research Participants

Each research participant was given a pseudonym to protect anonymity. As noted earlier in the document, the operational definition of an orphan, in the African context, is a child who has lost one or both parents to death. Shisana, et al. (2006) explained this definition in terms of the impact upon the African child of the death of even one parent. This loss in a low resource environment often results in severe emotional and material deprivation. In addition, AIDS orphans, like those in this study, often are left with, or care for, a sick remaining parent. Such children are called, therefore, single orphans or double orphans (Shisana, et al., 2006). The chart below lists basic descriptive information about and physical impressions of the chosen research participants.

Table 2
Research Participants

Child Code-Pseudonym	Age	Sex	Living Situation	Physical Condition
A- Agness	9	Fe	Orphanage since age 5. Remembers living with grandmother.	Age appropriate. No visible signs of disease.
B- Brenda	9	Fe	Orphanage since age 6. Remembers and still in contact with grandmother.	Age Appropriate. Tall. Some facial warts.
C- Godfrey	12	M	Orphanage since age 9. Still in contact with older brother.	Extremely small for age. Some clubbing of fingers.
D- Eliata	11	M	Orphanage for 5 months. Mother died in Tanzania. Father is lost to follow up in Kenya.	Age appropriate, but a bit short. No visible signs of disease.
E- Ibrahim	12	M	Orphanage since age 9. Still in contact with older brother.	Age appropriate. Some visible swelling of parotid glands and neck.
F- Evaline	11	Fe	Orphanage since age 8. Reconnected to sisters and grandmother one year ago.	Age appropriate. No visible signs of disease. Extremely quiet.
G- Gaspar	11	M	Custody of uncle (alcoholic) but really lives with neighbors. Sister lives with a different neighbor. Father lost to follow up.	Very short and small boned for age. Some visible swelling of parotid glands.
H-Hilda	12	Fe	Father- quite ill with AIDS	Age appropriate. Persistent cough, swollen parotids and neck, dark circles under eyes. Difficulty swallowing-possible oral problems.
I-Maria	9	Fe	Mother and older sister- all 3 infected.	Age appropriate- no visible signs of disease.

J-John	9	M	Mother and one older sister	Seems very young for age. Persistent cough.
K-Frida	12	Fe	Uncle and his wife, cousin	Age appropriate. Slow responses. Cough.
L-Wilson	9	M	Grandmother, older sister (also infected)	Age appropriate. Persistent cough. Seems very bright.

Interviews

Interviews of Orphanage Participants

The first set of interviews of participants living at the orphanage was conducted on February 21, 2009. The office of the executive director was used for this purpose. In preparation for the interviews, a table and two chairs were set up. On the table were Legos blocks, a few small trucks and cars, drawing paper with both markers and colored pencils, and a Sony Microcassette-Corder with external microphone. After greeting the child, the interviewer began to ask the questions as they appeared on the Interview Script. The only variability in use of the script was the occasional change in ordering of the questions as seemed appropriate to the interviewer based upon the participant's apparent unwillingness to answer, or because some questions seem to naturally flow into each other. The entire interaction was audio tape recorded, with the recorder in plain view. None of the participants manifested shyness with the audio recording process, although some were more generally outgoing than others in their responses and interactions with the interviewer. The head researcher was present, seated at some distance from the table so that she could observe and take notes on the child and the interview process. Although snacks were available and visible during the interview, no participants needed or requested a break. After the interview was completed, each child was given a juice box

and a muffin. The second set of interviews occurred on February 28, 2009, and followed the same process. At the end of each interview in the second meeting, the participant was given the drawing pad and markers they had used, as well as a t shirt. Snacks were again supplied.

Interviews of Village Participants

The first set of interviews with children living in village settings were conducted February 24 to 26, 2009. Because these interviews occurred in each child's home, settings were variable. Guardians had assured the team of privacy, which in all cases meant the interviews were conducted in the home while other family members remained outside. Any available surface was used for placement of the audio tape recorder and toys, and chairs, beds, or couches were used for seating. After some conversation to set the participant at ease, the interviewer began to ask the questions as they appeared on the Interview Script. The only variability in use of the script was the occasional change in ordering of the questions as seemed appropriate to the interviewer based upon the participant's apparent unwillingness to answer, or because some questions seem to naturally flow into each other. The entire interaction was audio tape recorded, with the recorder in plain view. None of the participants manifested shyness with the audio recording process, although some were more generally outgoing than others in their interactions. None of the participants needed or requested a break. At the end of each of these meetings, snacks were distributed to all household members who were present.

The second set of interviews with participants living in village settings occurred on March 4 and 5, 2009. These took place in the Tanzania Project office in Patandi

Village. Because of the distances and variability in travel time for participants and guardians, several guardians requested that there be no set time prearranged for individual participants. When queried about issues of confidentiality regarding this request, the guardians unanimously agreed, when individually polled, that it was important to them to have the flexibility of arrival time that allowed for other obligations to be met, and for them to accompany their own child rather than sending them with research team members. When the head researcher and research assistant arrived on the first day, several participants and guardians were already waiting. The children were playing together and seemed cheerful and relaxed. Set up for these interviews involved placement of Legos and toys as well the audio tape recorder on the table, accompanied by chairs for the interviewer and participant. The head researcher sat well back from the table. At the end of each interview in this series, the participant was given snacks, the drawing pad and markers they had used, and a t-shirt. The accompanying adult was given travel reimbursement as well as a small bag in which was a kilogram of rice, a kilogram of sugar, and a bar of soap.

Data Tracking Systems

Audio tapes were labeled with a coded letter and number at the end of each interview. Subsequently, each group of tapes was delivered to the transcriber/translator. When translation of each tape had been accomplished, the Kiswahili transcriptions and English translations were sent via email to a coded email address accessible only by the head researcher. In each case, the original audio tapes were delivered back to the head researcher the day after completion of the work. Tapes were then kept in a locked cabinet

in the Tanzania Project office until their removal to the locked cabinet in the office of the head research in Santa Fe, New Mexico, USA. All translations were completed by March 21, 2009. Once the head researcher confirmed that all transcripts and translations had been completed and received, the transcriber/translator was instructed to delete all transcriptions and translations from his personal computer. In addition to the audio tape recordings, notes made by the head researcher and drawings completed by the participants were kept in a locked cabinet in the Tanzania Project office until their removal to the locked cabinet in the office of the head research in Santa Fe, New Mexico, USA.

Data Analysis

Phenomenological Data Analysis Method

Moustakis' 1994 modification of the Stevick-Colaizzi-Keen Method was used as a basis for data analysis in this study. This researcher implemented the selected steps below with verbatim transcripts:

1. Consider each statement with respect to significance for description of the experience.
2. Record all relevant statements.
3. List each non-repetitive, non-overlapping statement. These are the invariant horizons or meaning units of the experience.
4. Relate and cluster the invariant meaning units into themes.
5. Synthesize the invariant meaning units and themes into a description of the textures of the experience. Include verbatim examples.
6. Reflect on [the] textural description. Through imaginative variation, construct a description of the structures of [the] experience.

7. From the verbatim transcript of the experience of each of the co-researchers, complete the above steps.

8. From the individual textural-structural descriptions of all co-researchers' experiences, construct a composite textural-structural description of the meanings and essences of the experience, integrating all individual textural-structural descriptions into a universal description of the experience representing the group as a whole (pp.121-122.).

Research Log

From the beginning of the preparatory activities through data collection and analysis, this researcher made notes in a research log of ideas, questions, and pertinent observations that might assist in generation of the phenomenological description. These were often hand written in a notebook during the day as field notes, and later transferred to the digital log. In the log I also noted premature conclusions about the meaning of the data and attitudes that needed to be bracketed from the data analysis process. Much time was spent in reflective meditation, both during the data collection and data analysis phase. An excerpt from the log appears as Appendix F**.**

Data Coding

Data coding was a multi-step process. After multiple readings of entire transcripts, 125 code words were identified. An excerpted section of one transcript appears as Appendix G. Several additional passes through all transcripts then yielded each appearance of the code words. No data were viewed as discrepant, as all data are equally valid in phenomenological description. Code words were then color grouped and clustered according to themes that emerged from each appearance of the code in the data.

Thematic tables were then created of the participants' verbatim use of the clustered code words. An example of one such table appears as Appendix I. Subsequently, these clusters, and the themes they revealed, were correlated to the primary focus of each research sub-question.

Multiple passes and independent reflection on the resultant tables revealed the final formulation of the 7 themes that arose from the data. They include: the impact of HIV positive orphanhood upon basic quality of life, the physical impact of HIV positive orphanhood, the intellectual impact of HIV positive orphanhood, the emotional impact of HIV positive orphanhood, the social impact of HIV positive orphanhood, issues of agency, and the personal qualities and adaptive behaviors that the participants display in response to HIV positive orphanhood. All of these themes are located within the Tanzanian context. Each theme will be discussed individually and followed by textural-structural descriptions that give an overview of the lifeworld of 4 HIV positive Tanzanian orphans.

Individual Textural and Structural Portraits

As part of the phenomenological reductive process, the constellation of responses provided by each participant were synthesized to create coherent individual textural-structural portraits. This activity included much reflection upon the ways in which various attributes of the experience of HIV positive orphanhood intersected and acted upon others in each individual. This step of data analysis was completed for all participants. Two such representative descriptions are included below from the pool of participants living at the orphanage and two from participants living in the villages in an

attempt to provide a picture of the life world of the participants but avoid redundancy. A comprehensive analysis of the findings follows.

A Portrait of Agness

Agness was a 9 year old girl who had lived in the orphanage for nearly 5 years. Although she was abandoned at the gate, she remembered both the death of her mother and living with her grandmother. She was age appropriate in appearance, and seems healthy. Agness revealed that she tires easily, but rarely misses school due to illness. Although she does miss school to attend monthly HIV clinic appointments, she saw them as welcomed breaks from the stress of dealing with classmates. She acknowledged that all of her food, shelter, and healthcare needs are being met at the orphanage. About her arrival at the orphanage Agness remembered: "I mean me, I mean like when my mother died I was caught with a lot of bitterness. I was saying like this- these as they close me here inside isn't it that I shall be scared?"

While coloring, Agness recalled her mother's death with intensity-

> She drank that tea. When she finished she told me, Agness, time for break. She went she slept on the grass. Me I went to wake her up, to wake her up, she does not wake up. She has died. I went inside I told grandmother like this; Mother! My mother has died. She went, she ran. Then they were there they came they buried her, when they put the body in the coffin, and me I went into the coffin. I went into the coffin, that time they wanted to put it now in the grave I shouted, waah! Waah! I got into the coffin of my mother, waah!

Agness said that she is bullied in school. She says,

> Them, they hate me. I don't know why. I mean even days when I play alone they just come they start to beat me. People look at me, why don't you resemble me? They come, they start to insult me. I just look at them."

In the meeting when the research team introduced the study, the team said we were going to talk about school. Agness blurted out that Sister James, her teacher, publicly told the students from the orphanage "you people of Holy Cross, you are demons." Agness reported wanting to sing but Sister James would not let them sing with the other children. Agness shared a desk with another child whom she reports said, "Move over you have the AIDS". Don't sit close to me." She has kept the fact that she takes medicine a secret from the other children at school "I don't tell a person." She reported that she does not see herself as equal to other children.

Agness thought that she performed well in school, comparably to her fellows. She believed that children like her do not receive help from teachers. She said, "She [the teacher] does not come [to help], you see those early mornings they have a job of insulting you. Big, big insults. She knows the head teacher will not chase her." Agness felt responsible for her own academic performance. As far as academic or other support from other children at school, Agness said that if she asked for help from her fellows, "those they will just beat me."

Although she had received many negative responses from others, Agness believed it was important to correct a bad situation rather than accept it. Conversely, even if she did not want to or thought what they are asking was not appropriate, she believed that it was important to show respect to the teacher and just do as they ask. She believed that if you have a problem it is good to ask for help. Agness occasionally turned to the other children or aunts at the orphanage for help. Agness' primary problem-solving techniques were to think problems through herself or pray. She said, "I mean it is like God wishes

you to get many blessings. Those others will just beat me." Agness had healthy expectations for the future including becoming rich, having many children, and an office with workers. She reported that she will accomplish those things on her own, with the pastor, angels, and God's help.

A Portrait of Godfrey

Godfrey was a 12 year old boy who had been living at the orphanage for 4 years. He was short for his age, and manifested some clubbing of his fingers. Godfrey had a persistent cough. He was still in contact with his older brother, who was recently married. Godfrey had persistent problems with his chest, recurrent pneumonias, and tightness and chest pain that inhibited his physical activity at times. Godfrey said that he sometimes missed school for as long as a week with chest infection, and returned to the classroom only to be met with the questions and potential for abuse from fellow students. Godfrey said, "If they knew they will despise you. They will say that you, you use medicines for what every day? I have nothing to tell them, but they will be asking themselves, they talk about you. Maybe others, if they know you go to clinic, they will insult you." He was more comfortable in the company of the other children living at the orphanage both as playmates and confidants. Godfrey was content to know that his basic and healthcare needs are provided at the orphanage.

Godfrey described the effects of orphanhood clearly. "It is a problem because when, if your parent has died you are, everything that is done to you, you find what; you cannot do anything because there is no one to speak for you." When asked if he had ever

experienced hunger when there was no food available, Godfrey told the following story about his experience before coming to live at the orphanage:

> Home I was living with one mother; she used to give me jobs of chicken. Her, she goes to liquor clubs, she drinks. Now me, when I return from school, I fetch water, I collect firewood, and chicken I close them inside. She does not give me food. She can cook, but she does not remember you.

Godfrey believed that adults are good resources for problem solving and assistance. He thought that it was better to correct a bad situation rather than accept it, and that it was good to ask for assistance when needed. He used the aunts as healthcare resources, and the director of the orphanage as well as the counselor for matters of education, social conflict, and future planning. Although Godfrey acknowledged that he struggles in school, he believed that teachers can, and should, assist him to perform better. Godfrey said, "Yes it is important [to get help from the teacher] because there are those when they do wrong they don't know the place, they do not know the mistake." Yet this endeavor does not always meet with success, and Godfrey does not see the teacher as a reliable source of support. "If teacher he is tired, now if you go there he tells you, you are disturbing me for what, you cannot ask me a question some other time? He says, 'You, everyday you ask, you don't understand? "

Godfrey loves rap music and performance, and he said that, until recently, his future goals included becoming an actor. Godfrey said that the director of the orphanage had told him he must continue his formal education into secondary school instead of vocational training, so he then said he will become a scientist. It is unclear if he is committed to this goal, since he did not feel that he is very good at schoolwork. Godfrey acknowledged that his guardian (the director) will be instrumental to securing his future.

Godfrey saw himself as essentially the same as other children. He said, “Me, I see I am just okay. They have clothes for school, and me, I have them. They have what…shoes for school, and me, I have them! We are the same.”

A Portrait of Wilson

Wilson was a bright 9 year old boy who lived with his HIV infected older sister, a cousin, and an aged grandmother in a rural village. He was physically age appropriate and had no visible signs of disease except for a persistent cough. Wilson reported that he suffers from occasional headache and tightness or pain in his chest. Wilson regularly attends the HIV clinic, but expressed no negative emotion about it or taking daily medication. When there was no food available and Wilson was hungry, he reported that he responded by self soothing, and drinking water. Normally he expected to eat two times per day, and had access to basic necessities, such as a blanket, mosquito net and nearby drinking water. When he was ill, he told his grandmother, then went to school himself to tell the teacher he was not going to be attending that day. Often he was required to work at home even if he was not feeling well. He said that his grandmother was “a little bit” responsible for his health.

Wilson felt quite good about his academic abilities, competent to meet the teacher’s and his own expectations, and said that he is happy to help his fellow pupils when they have trouble in school, especially in mathematics. He got along well with his peers, and reported that he **“**talks with my colleagues to solve it’ when he has a problem.

Wilson was vocal on the issues of orphanhood. He said,

> Like others who miss a place to live, they have no parents, is bad luck. You get them maybe they have a mother and me I have no mother. Them they get

> they have father, me, I don't have. You find them they get food, you find me, I don't have. You find they know many things, me I don't know because you find they have been instructed by their parents. Now me I have no parents. Some they are helped by their relatives, but I am not helped. You find my fellow children live a good life and me I live a bad life.

Wilson's frame of reference for many things in his life was God's will. He believed that being sick with HIV, as he is, was God's will as well as bad luck. In addition, he counted on God to help him in his future pursuits. Wilson believed it was good to ask for assistance with problems, and it was wise to correct a bad situation rather than accepting it. Wilson supported the idea that teachers, and all elders, "are supposed" to be treated with unexamined respect simply because they are elders. He reported that if he were to ask for help, he would ask his uncle, sister, or grandmother. This idea is in some conflict with his revelation of poor treatment by his aunt and uncle, who live nearby. Wilson's uncle has repeatedly forbidden him to go to school if help was needed at home with agricultural chores. Wilson tearfully told the interviewer that his uncle had sold his school shoes to purchase other things, and that he was now forced to go to school in flip-flops, to the derision of his school mates. Wilson said,

> You will find, I mean, where you stay they don't like you. Like uncle, you find he scolds us, if we do something small, he scolds us. Small mother [aunt] Diana we are insulted, me and my sister. She tells me, 'you idiot, you are doing things like a small child.' Grandmother tells her she should stop insulting us because we are sick."

The fact that he was forced to use a bowl and cup designated just for his use is demonstration of a stigmatizing response to Wilson's illness by adults in the home environment.

About his future, Wilson said he would like it to be good. He expected to do different jobs like farming and other things where he can be paid. Wilson also wanted to help his family, and expected to be the one who is in charge of creating his future life, without help from anyone other than God.

A Portrait of Hilda

Hilda was a tall 12 year old girl on the threshold of adolescence. She had dark circles under her eyes, swollen parotid glands and neck that make it difficult for her to swallow, as well as a persistent cough. Hilda lived in a rural village with her younger sister and mother, both of whom are also HIV infected. Hilda reported pain in her neck as well as tightness and occasional pain in her chest. She said that when she begins to cough it is difficult to stop, which can interfere with physical activity. Hilda believed that being sick is bad luck. She has witnessed others die, and fears for herself. Although Hilda reported that there are bed nets and blankets in the home, both are old and have been mended many times. She described her school uniform as old and torn in places. Water is available nearby, and the children in this family generally eat 2 meals each day.

Hilda reported that she has female friends, but the males “look at me like a rotten thing.” She did not know why this is so. She was glad that her mother was still alive because orphans “do not get upbringing like what her parent would provide to her.” Hilda reported that her primary healthcare practice is to take medicine and report to the clinic for refills, and said that her mother really does not contribute to her healthcare needs except by “consoling” her. Hilda believed she has some control over whether she becomes sick or stays well, and listens carefully to instructions given by her doctor. Hilda

believed it was good to ask for help, and if she decided to ask for help, turned to her mother. Usually, however, she solved her problems herself- whether they be the need to work harder in school, or the personal behaviors she has developed in response to unmitigated hunger.

Hilda believed that her ability in school made her the same as other children, although she did not rate herself at the top of her class. She was comfortable approaching other students for help. Hilda has not approached her teachers for assistance, saying "it depends on the teacher himself. ….you find each teacher with his own behavior**",** and indicated her discomfort in predicting a positive response from teachers. Hilda had autonomous ideas about a child's right to choose the correct path for herself, even in a situation with a teacher. However, she also said that she is "supposed to respect the teacher and listen to what she is told because the teacher is my elder."

Hilda wanted to have a good job in the future, and help her mother. She believed the best way to get there would be to study hard and take her medicine rigorously. Hilda said that her future is in her own hands, with the help of God.

Themes

Theme One: The Impact of HIV Positive Orphanhood on Quality of Life

In order to garner data about the basic quality of life of the participants I created two levels of questions. The first assessed access to water, food, shelter, blankets, school uniforms, and mosquito nets. A second level of questions ascertained health-related quality of life, and probed such factors as fatigue, pain, school missed for health reasons, and sleep disturbances. Health related quality of life will be discussed in the section on

the physical impact of HIV positive orphanhood. A global picture of the quality of life experienced by these children will be described as part of the synthesized experience of the phenomenon.

The participants living at the orphanage reported that all of their basic needs are provided by orphanage staff, and are not of concern. They eat at least three times each day, and receive frequent healthy snacks to accommodate the increased hunger experienced by people using anti-retroviral medication. Participants live in a clean facility, each sleep in a separate bed with blanket and bed net, perform little in the way of housework, and are provided school uniforms and transport.

All participants living in the villages have close access to water. They generally have black tea or tea with milk in the morning, and eat two meals each day unless, as Hilda said, "you find mother doesn't have money… she doesn't have even money for buying food." Only one participant reported a functional bed net. The remainder said that nets were missing or torn. Half of the children have a blanket; the other half report using a sheet or kanga (native light cotton cloth). All but one of the village participants said they had no uniform, their uniform was "of a long time ago", was bad, or missing components, like socks, shoes, or sweaters. Gaspar said, "No, I wear only a blue shorts and one white shirt of home that is old." Uniforms are required at all schools, so for two participants lack of the appropriate uniform has impeded participants from regular school attendance.

Tanzania is a poor country, where the average household income is 770 USD (World Bank, 2006). The finding that participants living in the villages are poor, and

suffer some deficits in basic quality of life, is not surprising. Without further investigation into whether the households in which the participants live experience greater than average poverty, concomitant food insecurity and other poor living conditions, it is impossible to know whether the participants' experience in this realm is connected to HIV positive orphan status or a function of other factors.

Theme Two: The Physical Impact of HIV Positive Orphanhood

The physical realm of life as an HIV positive orphan encompasses the disease-related aspects of the experience, personal health care responses to it, how orphanhood relates to healthcare, and how the participants experience the challenges imposed by the illness in their life. All participants were aware of their HIV positive status. Most have known for years that they carry the virus, while one participant had been diagnosed in recent weeks after more than a year of recurrent infections eventually linked to HIV infection. Symptoms of active infection with HIV or AIDS varied from the fatigue and hunger reported by nearly all the participants to the clubbing of digits evident in only one. Several of the children were quite short in stature, but whether this was due to poor antenatal nutrition or HIV disease is unknown. The constellation of chest pain, shortness of breath, and coughing was reported by all symptomatic participants to varying degrees. The next most commonly described or observed physical effect of HIV infection was swollen lymph and parotid glands in the neck, which participants said caused severe pain and difficulty swallowing. Half of the participants noted recurrent headaches or pain in the lower extremities. One participant had pervasive facial warts, while one other had dark circles under her eyes. One child living at the orphanage was completely asymptomatic.

Ten of the 12 participants currently take antiretroviral medication two times each day, morning and night. Some of them also take medication for various opportunistic infections, and the participants living at the orphanage take vitamins. All participants see the fact that they are sick as closely linked with the need and importance of taking their medicine rigorously, and being consistent with monthly clinic visits to obtain medication. It is unclear whether this is a learned behavior or part of their personal adaptation to living with a chronic disease. None of the participants expressed the belief that they will be cured of their disease, yet none of them talked about the fact that HIV is known to be linked to early death. In nearly all conversations about being sick, participants linked sickness with medicine and/or prayer, not death. Several participants included taking medicine as an important behavior when talking about how they will reach their future goals.

Fatigue and hunger were the two most pervasive effects of HIV infection and treatment mentioned by participants. Fatigue manifested in lack of endurance during play or other physical activity and the need to sleep more. Ibrahim said, “When playing, sometimes you find you are tired. Like if I am tired walking from school coming home. Also when I am [feeling] sick I don’t play.” The participants at the orphanage are supported in these needs by van transport to and from school and an expected after school nap. Hunger was a more intractable problem for some participants. Among other effects, anti-retroviral medication causes increased appetite. The majority of participants spoke about the need to eat well to combat the effects of their disease, showing that they were aware of the interplay between health and nutrition. For the participants living at the

orphanage, hunger and good nutrition were mentioned as problems experienced before they came to live there. The children living in village settings were, however, uniformly poor, so these participants reported unmitigated hunger and limited dietary choices they meet with self-soothing behaviors such as chewing leaves, drinking tea, or playing to distract themselves.

Eight of the participants had been hospitalized either with opportunistic infections such as pneumonia or tuberculosis, or to modulate the type and dosages of medication. This led to social consequences with classmates. Some participants reported that they had missed school for a week or more when they were ill or needed to be hospitalized; others said that they coughed a lot at school, which led to questions about their health that were uncomfortable and left unanswered. All participants kept the fact that they take medication a secret from fellow students, teachers, and neighbors. “If others knew….they will despise you. They will say that you, you use medicines for what every day? (Godfrey).” Participants believed that they did not appear to be sick, specifically with HIV, and saw this as an asset to social integration.”I just stay as normal; a person doesn’t even know that I am sick” (Hilda). Maria said that even when she was sick, she normally went to school.

Theme Three: The Intellectual Impact of HIV Positive Orphanhood

The majority of participants felt that they performed adequately in school. Several cited variations of “I listen to my teacher well and am serious with my work (Brenda).” One participant proudly told the interviewer that she was number 7 out of her class of 70

(Evaline). A younger child felt so good about his intellectual prowess that he said "Me, I help others, those who miss. I mean if they miss in mathematics, I help them (Wilson)."

At the other end of the spectrum was Gaspar, who admitted that even at 12 years old he cannot read, does not write well, and avoided going to school on examination days. Other children reported that they are not smart, or perform poorly because they have had to miss school for illness or clinic attendance. Godfrey talked about how it feels, in his words, to be "not smart". "For example if you have no brains, or you don't understand, they laugh at you, they separate you. If you don't understand they will laugh at you (Godfrey)." For Maria, the impact was felt when she was not in the classroom because of a medical need. She said: "When I miss school to go to clinic I feel bad because lessons pass me. Then I will do it myself and fail, because I am stupid." Although close to half of the respondents noted some school difficulties, responses from the participants did not reveal any pattern in perceived intellectual ability that could be linked to HIV positive orphanhood.

Theme Four: The Emotional Impact of HIV Positive Orphanhood

Participants described the greatest emotional impact from issues that are a result of orphanhood. Those children who are without either living parent described feelings of grief that may interfere with daily functioning. Ibrahim said, "Sometime in class [he] wasn't listening very carefully because sometimes he thinks of how he has lost his father and mother." One commonly described painful and longstanding set of emotions engendered by orphanhood was feeling alone in the world and without support. Godfrey said, "If she does not live with her parent when she tells that father I have been tired, him,

uncle, he will not feel bad. [Why?] "Because he is not the one who has born her." Eliata described this set of emotions: "If a person has died you start to have fear. You think very much, you think ….how she used to take care of you, that she was giving you…things. You think, why has she died now?"

Although few participants described an explicit fear of death, those that did linked their fear to witnessing the death of parents or others to whom they were close. This worry was apparent in 2 participants living at the orphanage who expressed deep concern about another child who was currently hospitalized. Evaline, who has lost both parents and has witnessed the deaths of several other children from HIV/AIDS related conditions said, "I have fear….like just now John Bosco is sick. I am afraid if he will recover." Hilda, a village participant who witnessed the death of her mother and has an extremely ill father, was the only participant who spoke about the possibility of her own death, saying, "If I see that, and me [I am also sick], I fear for myself." Hilda made the cognitive leap from recognizing her own infection to the impact and outcome of the same infection in her parents.

Although depression is commonly described in the literature as a response found in orphaned children and children with chronic disease, few respondents described feelings or behaviors that might fall under this umbrella of symptoms. A participant who had lost his mother less than one year ago tried not to talk about her, and cried when he did. This was viewed as an appropriate grief response, not a sign of emotional dysfunction. Only one child described sleep difficulties and another said that he "didn't have pleasure of life (Gaspar)." All participants could describe plans for their future,

which evidenced hope. Yet Agness said, “Some know good lucks and bad lucks. Eeh! Me, I know bad lucks only, really”. Responses that relate to hope as an attitude that impacts successful functioning will be discussed in the section on theme 7.

One set of interview questions was designed to elicit the participants’ general comparison of themselves to other children. Initially, all participants expressed the opinion that they were just like other children. When probed, many participants said that they are different from others because they are sick. The majority also admitted that they felt different because they were parentless or poor. Evaline said it well: “Others have father and others have no father and mothers. It is a problem because those who do not have parents feel bad. Different from others. Me, I don’t have parents. Difference me, I am sick.” Even with the awareness of their life challenges, the participants did not report global feelings of inferiority. The fact that they do not feel that they appear physically different from other children plays a big factor in their positive comparison of themselves with others. Brenda said: “I am as normal, just like them. There is not any difference.”

When shame over life circumstances or infection was mentioned by participants, it was expressed as self-stigma. Eliata said, “I don’t give my story. It is bad to tell people. People will see, they will see you, you are stupid, bad. They give the story of the whole house and he stays naked. You give your story of medicines, you take out all.” None of the participants has told school mates or others about their use of medicine for fear of the social ramifications. Ibrahim said, “I don’t want them to know about my taking medicine, absolutely.”

Theme Five: The Social Impact of HIV Positive Orphanhood

Data were gathered about two of the social environments in which the participants function: school and place of residence. Within these locations, issues of inclusion, acceptance, and other attitudinal representations give the participants information about how they fit in the world, and what society is telling them about their identification as orphans infected with HIV. Perceived sources of support will be discussed in the section on agency.

Teachers often set the tone for social interaction in a classroom. The participants have had variable experiences with teachers. Some participants saw teachers as fair, while others viewed teachers as perpetrators of stigmatizing action or attitude. Most participants did not report incidents of direct discrimination from teachers. The negative attitudes that were described included exclusion from activities and public derision, as well as teachers' unwillingness to help students with their studies. Children who live at the orphanage attend a variety of local schools. Agness reported that her teacher, Sister James, would not allow the students from the orphanage to sing with the other children and made them stand aside. Ibrahim said, "Teacher, you get he discriminates you. You write well but he crossed you or you have got a question correct, he crosses you." When asked whether the reason a teacher does not help a child might be because of something he knows about the personal life of the child, Gaspar said, "I see teacher knows absolutely that. That he has no parents." inferring that the teacher can mistreat a student who is orphaned without fear of response from a parent.

Seven of the 12 participants reported discriminatory responses including teasing, avoidance, exclusion from games, bullying, insults, and humiliation from peers. The younger the child, the more bewildered they seemed by the treatment they received. The following represents a typical interchange with a 9 year old. “Others run away from me. Me, when I play with them, they just run away from me. **[**Why do you think that is?] I even don’t know (Brenda).” One village participant reported social derision he believed was poverty related, since he is teased at church because he has just one good shirt which he wears every week.

Some participants reported successful strategies for befriending peers. Evaline said, “It is easy because when you show them love and them they show love to me, I get many friends.” John said, “There are no children who run away from me. If I want a friend, I go, I get him, I join hands with him, and we talk together”. Proximity was also cited as a factor supportive of friendship, since most schools are overcrowded and students share desks. Wilson said, “You find we are sitting at one desk. Now on sitting at one desk, we can’t hate each other. And even others also they are my friends.”

Interestingly, the participants living in the orphanage experience more discriminatory social responses, both from teachers and peers, than the children living in the villages. Since the orphanage children attend a variety of local schools, depending upon their aptitude and age, that are not attached to the orphanage, this may be a result of the openness of the orphanage in sharing information about the students’ HIV status with school personnel. For instance, Ibrahim said: “There are others you find they talk about you. They say, ‘That child is sick.’ You see they stay far from me.” In contrast, some

village participants feel that keeping their HIV status a secret protects them in forming friendships. Frida said, “My colleagues at school, they don’t know I am sick. It is easy for me to get friends. Neither am I hated.” A determination that revelation of HIV status to peers influenced their willingness to become friends was not, however, within the scope of this study.

The orphanage is a closed system where all the residents share identification as orphaned and HIV infected. No in-house discriminatory events from staff were reported by participants. The village participants reported variable experiences. The three village participants who do not live with a parent reported being the object of discriminatory or stigmatizing action in their residence. These actions ranged from being insulted to being “treated like a slave (Gaspar).” Gaspar reports, “For example, if you are staying at somebody’s, ehe. When you finish eating you wash utensils and other children have eaten long time ago. They are sitting and you are the one who is doing work there outside, alone.” Another participant reported a work load that makes him very tired (Wilson). Maria expressed her opinion that orphans “live differently from other children …they do not get good care.” All three of the participants who do not live with a parent are required to use bowls and eating utensils that are designated just for their use. This practice derives from the erroneous, but widely held, belief that HIV infection can be passed by sharing food.

Theme Six: Issues of Agency

During the data gathering process it became apparent that the participants had experienced and developed ideas about sources of support or influence upon various

aspects of their lives. Participants' discussions on this topic can be divided into three steps: (a) beliefs about accepting or finding solutions to bad situations, (b) the decision to ask for help or solve problems without help, (c) and the sources of help if one were to ask.

The choice to accept or attempt to correct bad situations or problems. Although all but one participant believed that it is better to correct a bad situation than to accept it, further probing revealed that this belief was conditional. Situations where the participants felt no control were deemed beyond the scope of correction. This included events or conditions that were considered outcomes of good or bad luck. Two specific intractable situations were often mentioned by village participants- hunger and interactions with teachers.

The impact of luck. All the participants believe that most things happen because of good or bad luck. A majority of the participants feel they have been the victims of bad luck. Hilda said, "Disease me, I see it as bad luck. If a parent dies it is by bad luck and you become an orphaned child. Me, I don't know these things of good luck." The most commonly described luck-derived life condition was HIV infection. More than half of the respondents spontaneously described a link between luck and being sick. Other bad luck included being poor, death of parents, not having enough food, or not being able access education. Two children said that they only know bad luck, not any good luck. When asked to describe a situation that evidenced good luck, participants listed not being sick, having all one's school needs, being helped, or being liked by other children.

All participants have experienced hunger for which there seemed no resolution. For the children living at the orphanage, these experiences occurred before their arrival at the orphanage. Some participants in each setting reported that they tried to distract themselves by playing, doing homework, or sleeping. Others just accepted it. When asked if she tries not to think about food when she is hungry**,** Maria responded 'No, because I am used to it. Not to eat sometimes, if there isn't [food] I just say that is it, because there isn't."

Participants see teachers in a powerful role that should not be questioned. In Tanzanian culture, elders are to be respected, and teachers fall within this classification. Hilda said "she is only supposed to do what teacher says because she is supposed to respect the teacher and listen. She is told because they are our elders." This is not to say that participants always agreed with teachers. They simply accepted the reality that teachers hold position power, and that it is unwise to challenge it. The caveat in relationships with elders, whether they be teachers or other adults, is that Tanzanian children are responsive to the power dynamic whereby adults are perceived as being in control.

Living in a country where corporal punishment in the classroom is pervasive (Ndosi, personal communication, October 12, 2008), all the participants have witnessed the beating or caning of students in their schools and about half have been on the receiving end of the stick. They accept this situation, yet when asked if demand, punishment, negotiation, or explanation was the best way for a teacher to elicit the cooperation of a student, 8 of 12 chose negotiation or explanation. The remaining 4 of the

participants believed that punishment was the best, or accepted, way. Gaspar said, "Teacher will tell ….what thing he should do. Is he not bigger than him? If you don't do like this he beats you.**"** For this reason, interactions with teachers are not an arena in which these Tanzanian children seek to solve problems, but usually accept them as intractable.

The decision to ask for help. Although nine of the 12 participants believed that it is good to ask for help, they solved most of their problems themselves. Whether these children are self reliant or actually without trusted others is unknown. Gaspar said, "There is no person that I beg assistance." All but one of the children living in village settings was their own problem-solving resource. Interestingly, 2 of the older children living at the orphanage do ask for help from trusted elders. This may be linked to their having experienced successful interactions that have led to trust in the process. The remainder of the participants echoed the report of Eliata. "Usually I find a way without begging for assistance." John feels even more strongly. He said, "I do solve the problem myself. It is not good to beg help." The exception to the nearly universal self-reliance is the parallel belief that God, like the self, is a constant and available source of help. Participant belief in the utility of prayer and God will be further explored in the section on sources of assistance.

Sources of help. Although the majority of participants do not ask for help, all participants were asked to identify who they might engage in problem solving or future planning if they did decide to ask for help. The purpose of this set of questions was to identify lines of communication and support that might be developed to assist HIV

positive Tanzanian orphans. Respondents' answers resulted in four categories of persons who might be sources for help in problem solving or planning for the future, namely guardians or family members, teachers, friends, or God. Only one participant reported that she would ask her pastor for help, and none identified other community based persons such as village or other leaders.

The most commonly mentioned potential source of help or problem solving support was the guardian or a family member. For the participants living at the orphanage, half of the participants would use the caretakers for heath related problem solving, while the same proportion said they might use the director for help with planning or creating their future life. Participants living in the villages most often mentioned the surviving parent or relative with whom the child lives as a potential source of help or problem solving, and in 2 cases, for their future goals.

The majority of participants saw the teacher as a source of help with academic and social problems, but do not believe that such assistance really is available to them. Most participants believed that, in the end, their school- related success or failure was something they needed to attend to themselves, particularly because they would feel badly if they asked for help but did not receive it. Of the 2 children who responded that they did think it was good or important to get help from the teacher, Evaline also believed that if the teacher refused to help "maybe [it was] because he doesn't want her to do well because he hates her." The responses demonstrate interplay between seeing teachers as a source of help but the avoidance of the source for fear of refusal or other negative outcome.

Half of the participants living in each setting used their friends to discuss and solve problems. Ibrahim , who is at the orphanage, said, “There are times we help each other.” Hilda, who lives with her HIV infected mother, reported that when she has a problem sometimes “I tell my colleagues to try to solve it.” The scope of the research questions did not reveal what types of problems the participants bring to their peers, although 2 did say they felt comfortable asking friends for help with schoolwork.

Second in frequency only to the self, participants named God as a source they actually use for problem –solving and support. God was viewed as always available and reliable in this capacity, as compared to luck which is unknowable and unreliable. Maria said, “I pray to God to help me. If I get even any assistance or I am advised I can even solve any problem. I only ask God for assistance because He knows.” The belief that God was a ready support extended to issues of health. Brenda said**, “**God takes care of me. It is true you can control sickness because God helps you. You are wanted to work hard, then you get better and God will heal you.” When asked who will help the participants to reach their future goals, 2/3 said the entire burden will fall to themselves and God. The responses ranged from Eliata who said “God is who can help me” to Frida who said, about how she will reach her future goals, “It is God together with me if I put effort.” Participants expressed no reticence or barriers to asking for help from God, as opposed to people. In addition, one participant expressed the belief that angels and her pastor could be helpful in accessing God, and that all three would be instrumental to reaching her future goals.

Healthcare agency. Inasmuch as the participants were HIV positive children, and therefore in need of health monitoring or assistance, it was useful to explore who in their worlds provides the oversight and agency for their healthcare. All of the participants living at the orphanage acknowledged that orphanage staff was their basic healthcare provider, dispensing medicine, overseeing nutrition, and watching for signs or symptoms that indicate a crisis may be at hand. One participant said that he made the decision to attend school or not depending upon how he is feeling himself, but the remaining participants in this group rely upon the "aunts" to make this decision. Two thirds of the participants living at the orphanage also personally chose to participate in health related practices, such as exercise, sleep, or prayer. Agness said, "Aunt decides if not to go to school. But I mean like a day when I am sick I stay five hours sleeping, I don't wake up. I stay if I see I am still tired. Then I go to sit, I pray for myself, and then I recover."

Participants living with relatives or guardians told a different story. Half of these children said that they are responsible for their own health. They tell the responsible adult when they are unwell, and then may be taken to the hospital or clinic. However, in all these cases the participants report that, on days they are unwell, they go to the school themselves to tell the teacher that they will not attend that day. The half of the participants in this group who named an adult who is responsible for their health indicate that it is a limited role. Common responses were "Mother just consoles me" (Hilda), "Father doesn't help much" (Hilda) or "Grandmother is responsible for my health a little bit (Wilson)." All village participants take anti-retroviral medication daily and said that this is their primary healthcare practice.

Theme Seven: Personal Qualities and Adaptive Behaviors

Chapter 2 included several theories that may be used in describing the orientation of children to their life experience. These theories are learned resourcefulness, locus of control, hope theory, and resilience. In addition, some aspects of chronic disease theory cwere used to analyze the participants' responses to living with HIV. These theoretical constructs provide a window into the meanings embedded in the personal responses of the participants and are helpful descriptive tools for understanding the life world of the HIV Tanzanian orphan. The question of whether these qualities and responses are culturally embedded characteristics or responses to the stresses of HIV positive orphanhood cannot, however, be determined by this investigation.

Learned resourcefulness. Learned resourcefulness theory postulates that persons who are high in this characteristic cognitively develop responses to stressful situations that actually minimize the effect of the events. (Akgun, 2004). The participants in this study behaved in ways that illustrate high levels of this skill. In dealing with hunger, all but one of the participants demonstrated that they recognize the problem and have found ways to mitigate its effect. Hilda said, "I forget for myself. I do my work if we have been given work at school. If I get there is no food then I go on with my school work until evening. We even boil tea." Wilson said, **"**Won't I just drink water?"

A second arena in which the participants demonstrate learned resourcefulness is in response to the belief that teachers will not help students who are having trouble with their school work. Many responses to questions about how they might deal with a poor homework score if the teacher would not assist echoed that of Hilda who said, **"**I

wouldn't despair. I would just go on learning me, myself." Also, the finding that most respondents believed that teachers do not always know what is right for the student, but students can choose to conform to teachers wishes, shows that the participants have cognitively reduced the effect of the power imbalance between teacher and student, per Folkman (1986). Maria said, "Normally the pupils are supposed, are required to listen to the teacher. But me, I will listen to him. I will do what he says a bit, then I will tell teacher 'may I'." Ibrahim went a bit further in looking for solutions saying, "I must listen to my elder. But I can tell the teacher I don't like. We should talk together".

Locus of control. Locus of control theory centers upon the belief that one's life either is controlled by powerful others or by the individual him/herself (Rotter, 1966). Perception of external control is particularly pervasive in some of the basic conditions, such as food availability or HIV infection, of participant's lives. Regarding luck, Hilda said, "Something can happen by bad luck you have not expected- like how I am sick." About teachers, Evaline said, "Teacher should decide [what the student should do] because he wants to help her and because she is wanted to respect him." Although the participants spoke about the effect of luck, an external force, in the above conditions, or the control exercised by teachers, the majority saw themselves as in control of their own destiny.

Most of the participants believed that their academic careers and future are in their own hands. This supports postulated high levels of internality in the research participants. About school, Agness' response was representative of the majority of participants. She said, "If I get low grades it is my fault, me. Teacher does not help me,

you do alone." Frida believed that a child who performs badly is "told to work but doesn't want. She refuses to work and doesn't listen in class." All of the village participants said that they are, with the exception of severe health crisis, in charge of their own health. And, although participants did indicate that they believed it would be good to have some help with future goals, most spoke of their own responsibility for creating their future, some with the help of God. Hilda said, "It is myself to put much effort, and also God."

One of the tenets of locus of control theory holds that life under the effect of external forces is unpredictable and unknowable. This researcher, by bracketing her own experience of God as an unpredictable external source, was able to understand that for these participants God is quite the opposite. The children in this study saw God as an available and reliable source of help and guidance. Thus, as regards the effect of God as an external force upon their lives, the participants felt that their internal locus of control was supported by belief in a higher power, and some aspects of locus of control theory are not useful to this analysis.

Hope. The operative definition of hope theory states that hope is a cognitive process comprised of a reciprocally derived sense of successful pathways, i.e. "the ability to visualize goals", and a sense of agency, or "the determination to reach these goals" (Snyder, Harris, Anderson, Holleran, Irving, and Sigmon, et al., 1991, p. 570). The majority of the participants in this study exhibited both these components of hope. All of the participants described age-appropriate goal setting for the future. Ibrahim said, "It should be very good. To have car, have a house, children and work." Frida described her

work goals. **"**I request teaching. And maybe to sew clothes with a sewing machine." One third of the participants expressed the wish to make enough money to help their family. The goal most commonly named by the participants was the assurance of enough food for two meals a day.

The two activities most commonly mentioned as supportive to reaching their goals were continuing education and taking medicine. Seven of the 12 children specifically mentioned the need to continue with their studies. Gaspar said, "I need to study. I like my life to be good in future." In addition to education, nearly half of the children mentioned the importance of continuing to take medicine. Hilda said that in order to have the good life she envisions in the future, she will need to "study hard, and to swallow medicine." Several participants specifically said that they would not despair even if hard things happened along the way. Once again, the agency most often cited to reach those goals was the self and God. This finding is in line with some literature postulating that self efficacy and spirituality both support hopeful attitudes, particularly in dealing with illness.

Resilience. Researchers variously describe resilience, but agree that it can be defined generally as the process of positive adaptation to life challenges. Resilience is an umbrella concept that incorporates a variety of qualities and adaptive techniques described in particular detail in previous sections, above. Masten believed that resilience is most often present rather than absent, and found that resilient children were usually intelligent, easy going, confident, and high in self-efficacy (2001, 1990). Using the tenets of this theory, the HIV positive Tanzanian orphans exhibited many of the characteristics

of resilient children. It is important to remember the caution of Howard, et al (2006) that resilience occurs within cultural and social contexts, and perhaps these participants were responding to adverse circumstances in the way that the culture demands rather than exhibiting special ways of dealing with their lives that are unique to HIV positive orphans. That said, examples from previous sections support findings that the overwhelming majority of participants exhibit confidence in their ability to problem solve rather than being destroyed by negative events or circumstances, and see themselves as highly self-efficacious in that ability. The fact that the research participants identified trusted adults rather than institutional or formal sources as a place to go for help parallels Bushweiler's conclusions about resilient children when he analyzed Werner's (1982, 1995) longitudinal Hawaiian study (1995). The above findings support the call of Gerhardt, Walders, Rosenthal and Drotar to develop interventions that capitalize on the positive adaptation and resilient qualities of HIV positive Tanzanian orphans in the future (2004).

Chronic disease constructs. Chronic disease constructs provide insight into both the trajectory of adaptation to life with chronic disease as well as the qualities and skills that persons with chronic disease use to reach successful adaptation. Both Charmaz (1983) and Folkman, Lazarus, and Dunkel-Schetter (1996) provided models of the stages in adaptation to living with chronic disease. However, because this research was an assessment performed at a moment in time rather than longitudinally, it was not appropriate to use these tools in analysis of the information provided by these research

participants. Rather, chronic disease literature related to emotional responses and coping mechanisms is useful in describing the lifeworld of the HIV positive Tanzanian orphan.

Corbin and Strauss (1988) suggested that there are 3 types of work done by the person with a chronic disease: management of the illness itself, management of daily life, and the work of defining and accepting the meaning of life with chronic disease. It is possible to view the combination as a composite assessment of the quality of life of a person living with chronic disease. Eiser (2004) stated that quality of life in chronic disease is a subjective measurement impacted by the multiple fields of experience. Thus, the first lens through which to examine the chronic disease experience of the research participants is overall quality of life.

The chronic disease quality of life of the participants encompassed the physical, social, and emotional realms. Ten of the 12 participants acknowledged the need to take daily medication and many paid attention to nutrition, exercise, and prayer as practices that helped to manage the illness itself. The research participants spoke of the physical manifestations of their disease as very real. Eliata said, " When I play or run I breathe very much until I fail to play. Me, I'm pained by chest." Not only did the majority suffer limitations to activity and school attendance, they also lived with the strain of keeping their illness a secret to the greatest extent possible. Frida says, "My colleagues at school, they don't know I am sick. I am different from others the way I am sick. I don't tell a person." In the case of participants living at the orphanage, disclosure of HIV status to school officials has led to social isolation in some cases. The emotional component of participants' quality of life is manifested in the interplay between recognition of the

illness and ways they attempt to make sense of it. Although emotional stressors and strategies used for their mitigation will be addressed later in this document, the abiding hope that participants hold for the future is a noteworthy aspect of quality of life for these children. The participants did not conform to Brown and Lourie's postulated high levels of hopelessness in children living with chronic disease (2000).

The literature on chronic disease describes certain types of negative reactions commonly found in children reacting to the stress of living with chronic disease. They include depression, anger, hopelessness, and perceived external locus of control. Although I prefer Gerhardt et al. (2004) assertion that it is a disservice to use deficits-based models of these children as weak and vulnerable rather than adaptive and functional, it is important to view participant responses through both lenses.

Only one respondent provided evidence of global sadness that might be called depression, and it was not associated with chronic illness (2006). This finding is contrary to the work of some who have found links between mood disorders and chronic illness in children. No participants spoke of anger at being sick. Rather, the blame was assigned to bad luck, an external force that could not be controlled. This is one of very few areas where participants voiced a belief in an external locus of control.

The meaning of life with chronic disease is embedded in the local meaning of illness in general and any additional factors related to the specific illness in question. The participants are living with a widely stigmatized condition which has produced a secretive response in all of them. Participants supplied HIV infection as part of their self-description, albeit within a series of questions about how they were the same and how

they were different from their fellows. However, self-stigma as evidenced by the avoidance of illness disclosure or reason for school absence, refutes the possibility that participants have fully accepted their diagnosis. Keeping the secret, although stressful, is possible for the participants because, unlike children with other chronic illnesses, most participants do not have symptoms or overt physical manifestations of disease that reveal their status.

Boekaerts and Roder's (1999) meta-analysis of the literature found that children with chronic disease seem to utilize more cognitive and internalized responses to stress than their physically healthy peers. This theory is borne out by the participants in this study, 9 of whom relied on themselves for stress management and problem solving. Because they were largely self-directed and self-reliant, the participants acted in ways that evidenced internal locus of control. Miller and Wood postulated that chronically ill children who manage their own self care can achieve efficacy in multiple domains (1991). Participants living in the villages were doing just that. The participants living at the orphanage relied upon the caretakers for much of their health-related care, but still saw themselves as largely responsible for other aspects of their lives. In addition, the majority of participants in both settings demonstrated high levels of learned resourcefulness, a strategy that utilizes cognitive techniques to make sense of the world. These findings are consistent with some theory about techniques used for stress mitigation among children with chronic disease.

Charmaz (1988) postulated that the most crucial aspect of acceptance of the role of chronic disease in the life course is recognition of the limitation of choice and

freedom, which are important to self definition, imposed by the illness (1988). This belief is central to the meaning of chronic disease for each individual. More than half of the respondents spoke about the bad luck of being sick, and the limitations they experience regarding physical activity, school attendance, and social interaction. In looking forward, the majority of participants noted the importance of continuing to take medicine to ensure their health in the future. Knowing that one is tied to medicine for life may be viewed as a limitation, but was presented by the participants as just a necessary fact. Their responses paralleled those of the teens interviewed by Levert (1993). The teens advised their peers to take their medication correctly and consistently as well as to rely on themselves instead of others to know their limits and potential (Levert, 1993). The emotionally healthy response, then, to living with chronic disease is recognition of limits while exerting personal control of those aspects of the experience that can be controlled. Using this definition, and noting their young age, the participants in this research seemed to exhibit many characteristics and behaviors to support the view that they are progressing well in the work of integration of chronic disease into their view of themselves in the world.

Residence-Specific Data Comparison

Research sub-question (5) asks for a comparison of HIV infected Tanzanian orphans living in institutional settings with those living in village settings. This task was accomplished by a comparison of findings on key parameters explored above.

Quality of life. A quality of life determination includes measurement of the level at which basic human needs such as food, shelter, clothing, and care are met. The

participants living at the orphanage reported that all of the above needs are being met. Food is plentiful, the facility is clean and adequate to the number of persons who live there, and education and healthcare are provided. Participants living in the villages generally eat 2 times per day, and reported frequent lack of food in the household. Two thirds reported that clothing was old or in disrepair, and half were without a blanket. Although all village children attended school, half reported either missing school in order to work at home or older age at enrollment. Participants living in the villages monitored their own health and only received support if they were very sick.

Physical impact. Children living in both settings reported a similar set of symptoms and physical limitations. Although participants in both settings took anti-retroviral drugs, those living at the orphanage also took vitamins and had ready access on-site to medication for secondary infections. Village children must travel to the clinic to be treated for secondary infection. Daily assessment of health and suspicious symptoms was performed on each participant living in the orphanage. No such assessment was performed on village participants.

The response of adults to the physical needs of HIV positive children is markedly different between the two settings. In recognition of the limited stamina of children with HIV, St Lucia Nursing Home and Orphanage provided van transport for the children to and from school and healthcare appointments. All participants living at the orphanage took a daily nap, and did not perform rigorous chores. Participants living in the villages walk to school and clinic, and performed many tasks, such as gathering firewood and tending to animals. One half of the village participants reported that they even walk to

school when they are ill to inform the teacher that they will not be attending that day. Regarding the hunger that is endemic to those taking antiretroviral drugs, all participants living at the orphanage said that they could meet their hunger, but half remembered times when they went hungry before they came to live there. All participants living in the villages reported unmitigated hunger and limited food choices.

Intellectual impact. Five of the six participants living at the orphanage reported that they are performing as well as their peers in school. Four of the 6 participants living in the villages reported that they are performing as well as their peers in school. Thus, there was very little difference in perceived intellectual ability between the children living in the two different settings. However, the 2 village participants who reported school difficulties indicated severe educational lag, such as the inability to read and write at 12 years of age. Both sets of participants reported the negative impact of having to miss class for clinic appointments, a result of HIV infection. However, as noted above, intellectual achievement in this sample cannot be correlated to HIV positive orphanhood and may instead just be the result of individual differences.

Emotional impact. Few participants linked HIV infection with death. The participants living at the orphanage were, however, in close contact with a concentrated group of sick persons, and have witnessed life threatening illness often. The majority of the participants living in the orphanage spoke about their fear that someone they know will die, or they have experienced the death of someone to whom they were close. Only one participant living in the villages acknowledged first- hand knowledge and fear of her

own death. The two groups of participants were nearly identical in their report of other emotional concerns and difficulties.

Social impact. Participants were asked to describe their social interactions at home and school. As expected, no at-home stigmatization from peers or staff was reported by the participants living at the orphanage because all residents are HIV positive and orphaned. The half of the village participants who did not live with a parent reported variable discriminatory actions from guardians or others living in the home.

The social experience at school or elsewhere outside of the orphanage for children who lived at the orphanage was, more often than not, challenging. This researcher postulates a link between disclosure of the HIV status of the participants to the school officials and the discriminatory treatment by teachers and students reported by all but one of these children. Half of the village participants cited incidents of avoidance or other discriminatory actions from fellow students. Because the HIV status of these participants has not been disclosed to teachers or peers, the reactions may be due to orphanhood or some other cause.

Agency. Nearly all participants believed it was good to try to correct a bad situation rather than live with it. All participants believed in the influence of luck upon their lives, and agreed that being sick was such an example. Regarding the idea of seeking help, some participants living at the orphanage believed help was available from the aunts or the director. This researcher noted the strongest such response from the older orphanage-dwelling children, who may have had more experience with their desire for help having been met in a positive fashion. However, a nearly even number of

participants living in each setting said that they relied most of all upon themselves. If they did decide to ask for help, half of the participants living at the orphanage would use the aunts for healthcare problem solving or the director for future planning. Participants living in the villages identified the living parent, or other relatives or guardians as possible sources of generalized problem solving support. Half of each set of participants said they would turn to peers for problem solving. All but one child out of the total identified God as a source of help. Thus, in the areas outlined above there is very little difference between participants living in each setting.

There was, however, a difference between the two groups when it came to healthcare agency. All of the participants living at the orphanage saw the "aunts" as reliable healthcare providers, both in day- to- day care as well as decision making about the need for professional medical attention. Among participants living in the villages, more than half said that they personally were responsible for their own day to day healthcare. These children relied upon adults for health support only when they were sick enough to need professional care. Village dwelling participants saw caretakers as having a quite limited role in health care provision.

Personal qualities and adaptive behavior. No differences between the 2 groups were uncovered using the tenets of learned resourcefulness, locus of control, hope, or resilience theory. Differences between the 2 groups' adaptation to life with chronic illness were most evident in the social realm, and have been discussed in depth, above. Because participants living in the villages are, of necessity, functioning with high levels of personal efficacy, it is possible that they are more positively adapted to living with

chronic illness than are their fellows at the orphanage. Further study is needed to support this contention.

Thus, participants living at the orphanage and participants living in the villages did exhibit some differences in their perceived lifeworld. Orphanage dwelling participants enjoyed higher quality of life and health care support from adults than their fellows in the villages. They did, however, face greater challenges in social interactions with others, due to the fact that the outside world is aware of both their orphanhood and HIV illness simply because of their place of residence. Although comfortable where they live, they are forced to negotiate between the two worlds in a way that village children are not. This researcher postulates a differential level of adaptation to orphanhood and HIV status between the two groups.

Synthesis of Textural and Structural Data

Participants believed that, to a large extent, their basic needs were being met. This was less true for those living in the villages where clothing, bed coverings, and food security were issues. Most of the participants have known their HIV status for some time, and report fatigue, headache, chest complaints and hunger as chronic physical symptoms. These symptoms limited their stamina, but have not severely affected their feelings of productivity. They view medication, good nutrition, and prayer as keys to health and are not preoccupied with thoughts of increased debilitation or death.

With few exceptions, participants viewed themselves as functioning as well as their peers in school performance. They were concerned, however, about the impact on both their education and social interactions of missing school for clinic appointments or

illness. Participants felt responsible for their own level of performance and did not generally expect or attempt to access assistance with educational needs from teachers.

Orphanhood played a major role in the emotional life of participants. Grief and feeling alone were painful emotions described by most participants. In some cases, the social responses of others reinforced the participants' sense of being without support or care. Participants saw themselves as the same as other children except in their identification as orphaned and HIV positive. Self- stigma about these issues was pervasive and affected social interactions, since participants become secretive. Yet when treated in stigmatizing ways by peers, teachers, or caretakers they are often bewildered as to the reason. Even in the face of these facts, the participants do not report generalized feelings of inferiority or depression and are hopeful about reaching future goals.

Participants believed in correcting a bad situation rather than trying to accept it. They did, however, believe in the power of luck and saw it as a force that cannot be controlled or affected by the individual. Importantly, examples of bad luck mentioned by the majority of participants were food availability, death of parents and HIV infection. One arena where accepting a bad situation made sense to participants was in interactions with powerful adults, such as teachers, since Tanzanian children are taught from an early age to respect elders. They did not, however, believe that elders were universally right in their determinations, but did believe discussion or negotiation were desirable, though rarely used, ways to solve conflict.

Ten of the twelve participants solved the majority of their problems themselves, or with God's help. They saw God as reliable and available for this purpose. If they did

decide to ask other persons for help in reaching goals or for problem solving assistance, participants said they would turn to family members or caretakers, or sometimes to peers. Although teachers were seen as a resource for these functions, participants did not believe that assistance by teachers was really available to them. Participants living at the orphanage utilizedthe caretakers for healthcare support, while those living in the villages, to a great extent, assumed this function themselves.

Participants were self-reliant, and have cognitively developed methods that help them function as HIV positive and orphaned in their world. They were engaged in the "planful problem solving" (Akgun, 2004, p. 445) of learned resourcefulness. Although participants believed that the external force of luck had saddled them with both their diagnosis and orphanhood, their responses were predominately internally perceived and generated. Supported by hope, participants utilized these methods and qualities as they visualize and planned to reach future goals. These highly resilient participants continue to adapt to the challenges of their life conditions. In adaptation to life with a chronic illness, participants have incorporated HIV- infected into their self-description, yet their self stigma, supported by social stigma, was a barrier to integration and acceptance of the meaning of this state of affairs. They were, however, well on the way to this goal, given their young age.

Evidence of Quality

Quality in phenomenological research is determined by very different criteria than other types of investigation. Standard measures of validity and generalizability do not apply, but need to be replaced with measures appropriate to this very specialized method.

Moustakis (1994) says that phenomenological methodology is "a return to experience in order to obtain comprehensive descriptions that provide the basis for a reflective structural analysis that portrays the essences of the experience" (p. 13). The key aspect of this process is making sure that the participants do not disappear while interpretation and structural analysis occurs, as they are the source of understanding of the phenomenon and must remain visible throughout (Moustakis, 1994).

Van Manen (1994) provides a guide to the process that supports the quality of the phenomenological investigation. The six research activities he delineates are:

1.Turning to the phenomenon which seriously interests us and commits us to world,

2. Investigating experience as we live it rather than as we conceptualize it,

3.Reflecting on the essential themes which characterize the phenomenon,

4. Describing the phenomenon through the art of writing and rewriting,

5.Maintaining a strong and oriented pedagogical relation to the phenomenon, and

6. Balancing the research context by considering parts and whole (p. 30-31).

The steps in meeting the above goals have been followed with great attention. Data was collected and transcribed accurately. The material was approached without presupposition, and personal or cultural biases and judgments were immediately noted in the log as a way to remove them from the process. Participant report was viewed as the authentic source from which themes would emerge. Personal reflection and writing were both deep and prolonged processes that led to explication of the experience of the

phenomenon both for individual research participants and the group as a whole, what Moustakis (1994) called “creative synthesis” (p. 19). Because the process followed the prescribed steps dutifully, there is the possibility for duplication of the research that replaces generalizability, recognizing that the data generated in such duplication will be specific to the participants included.

Evidence of the above can be found in the following appendices:

1. Appendix F Excerpt from Research Log
2. Appendix G Excerpt from a Transcript
3. Appendix H Excerpt from a Data Analysis Table

Summary

Chapter 4 has described the experience of living as an HIV positive Tanzanian orphan through the eyes of 12 participants. In addition to individual voices, participant reports of the experience in various domains contributed to formulation of a composite of the experience. Further analysis using the tenets of locus of control, learned resourcefulness, hope theory, resilience, and chronic disease theory provided an additional layer to the description. Full explication of the data collection and analysis processes supported the quality of the findings. Chapter 5 will explore the meaning of the findings, areas in need of further investigation, and the social change implications of this body of work.

CHAPTER 5:

SUMMARY, CONCLUSION, AND RECOMMENDATIONS

Overview

The purpose of this study was to describe the lived experience of HIV positive orphaned Tanzanian children. To attain this goal, in depth interviews with 12 HIV positive Tanzanian orphans living in two types of settings were conducted**,** and a phenomenological approach to data analysis was undertaken. Identification of study participants was provided by two community partners with whom this researcher has ongoing relationships. The research team members were either trained by, or members of, the staff of a college-based child advocacy program. A professional transcriber/translator was used to facilitate translation of documents, including consent/assent forms, interview protocols, and transcripts of interviews, between English and Swahili. Field research was performed between February 1 and March 19, 2009. The structural textural description that was derived from the interviews was viewed as a necessary first step in understanding the difficulties encountered by these children so as to provide guidance for future service delivery and societal responses to meet the needs of HIV positive Tanzanian orphans.

A recent outcome analysis of 4 years of PEPFAR initiatives in Africa revealed that although a large number of deaths attributable to HIV have been averted, the prevalence of the disease is increasing due to two factors (Bendavid, E. and Bhattacharya, J. 2009). First, although the rate of new cases of HIV is decreasing, there continue to be many thousands of persons newly infected each year (Bendavid & Bhattacharya, 2009).

Secondly, and perhaps more importantly, the prolongation of life achieved through use of antiretroviral drugs means that there are an increasing number of HIV positive persons living in the world (Bendavid & Bhattacharya, 2009). These findings support the need to understand the challenges of the increasing numbers of both newly infected African children as well as the extended lifespan enjoyed by HIV positive African children with the support of pediatric formulations of antiretroviral medication. The recent recognition that large numbers of third world children are living and growing up HIV infected creates an urgent need for research that will support local and societal responses. In this study, the added burden of orphanhood was examined for possible interplay with HIV diagnosis in the lifeworld of the Tanzanian participants.

Interpretation of the Findings

Research Question Revisited

The findings of this investigation answer the research questions described earlier in this document:

What are the qualities of the physical, emotional, intellectual and social experience of living as an HIV-infected Tanzanian orphan?

1. How do HIV-infected Tanzanian orphans think they compare to other children (a) physically, (b) emotionally, (c) intellectually, and (d) socially?
2. How do HIV-infected Tanzanian orphans perceive what the society is telling them about their identification as orphans infected with HIV?
3. What factors are present that support these children in coping with both orphanhood and positive HIV status?

4. How do these children rate on standardized quality of life indicators?
5. How do HIV-infected Tanzanian orphans living in institutional settings compare on the above four parameters to similarly-described children living in village settings?

Chapter 4 described the very specific data that corresponds to the sub-questions. Interpretation of this data was meant to reveal the overarching description of the phenomenon as lived. The lifeworld of the HIV positive Tanzanian orphan is an interplay between aspects of the various domains of experience. Each is equally important and acts upon the others, so the composite description must be viewed as a system. For this reason it is best to interpret this data using a formula that describes aspects of the experience according to the domain in which they occur- internal or social- rather than as segmented by the research questions. The lifeworld of the participants will be discussed under the headings of the qualities of the internal experience and qualities of the external, or social, experience. A discussion of the qualities participants use to meet the experience, in response to sub-question c, follows.

Qualities of the Internal Experience

The internal experience of the participants was made up of their perceptions about their quality of life, and how they felt they compared to other children on physical, social, intellectual, and emotional parameters. Participants living at the orphanage felt secure in their knowledge that the basic necessities of life and school were provided to them. The good quality of life enjoyed by these children was a direct result of their HIV positive orphanhood, since it was their dual-condition that caused them to be placed at this

facility. This situation might be viewed as a positive effect of HIV positive orphanhood as compared to the effect of the phenomenon upon similarly described children living in the villages. For village children, the quality of life impact of HIV positive orphanhood was not as clear cut. With nearly universal poverty, the hunger, lack of school supplies, mosquito nets, or other material goods may not be a direct result of orphanhood and HIV diagnosis. Without further research one cannot know if this is the case or not, even though Miller et al. (2007) and others have found that orphans in some African countries uniformly live in poorer households than children who are not orphaned.Whichever is the case, HIV positive orphans living in the villages did suffer from the insecurity-derived stress of not knowing if or how basic necessities would be provided. These types of stressors have been known to have a negative effect upon physical health.

The physical experience of HIV required participants to reconcile low energy and chronic lung complaints to the expectations for active physical work and play of a normal Tanzanian child. Although the children have accommodated well to the idea of medication as a daily requirement, it was also a source of shame and a reminder of their chronic condition. The threat of secondary infection and thereby hospitalization added to the stress of life with a chronic illness. The children living at the orphanage received consistent monitoring and support of their health, which allowed more freedom for the work of being a child. Orphaned village children must not only be productive members of their household, but also must act on their own behalf regarding health and illness. The burden of orphanhood and illness was deeply felt by these children as they negotiated their daily lives.

No link was discovered between intellectual ability or perception of intellectual ability and HIV positive orphanhood. Most participants believed they perform as well as their peers. Although some participants said they wished they had more help from teachers, they generally felt good about being personally responsible for their success or failure in school.

Orphanhood has left all the participants, even those with a living parent, feeling alone in the world and without support. All children need and desire a person on whom they can rely (Laser & Leibowitz, 2009). Even those at the orphanage who said that role was filled by the caregivers clearly missed the support and sense of belonging they imagined would be forthcoming from a parent. Being HIV positive from birth made the situation doubly poignant, since the deceased parent had often left the disease, and little else, as their legacy.

The emotional impact of HIV positive orphanhood colored both the feelings and responses of these children. From grief over the loss of parents to pervasive self-stigma, the internal life of the participants was colored by their life conditions. They saw themselves as the same as other children until the identified shame-filled conditions were mentioned. This duality created a tension between the social integration they desired and self-acceptance.

The set of findings regarding agency give us insight into how these children desired to be helped. Because they felt that bad situations should not be endured but corrected, yet do not always see family members, guardians or teachers as reliable sources of help, they have inadvertently described a gap that exists in their experience. At

present there was nearly universal belief among the participants that the self and God are the only ones they can count on. This is a sad, albeit resilient, stance to uncover in young children. However, when conditions such as illness and orphanhoodwere described as an outcome of bad luck, these participants merely accepted the conditions without anger and looked to personally mitigating the effects rather than examining the cause. Over all, they have either decided or discovered that personal problem solving is the best, and perhaps only, option they have.

Qualities of the Social, or External, Experience

The social experience of the HIV positive orphaned Tanzanian child was most easily observed and described in the home and school. Although there are certainly aspects of social interaction in the village, church, or elsewhere, Tanzanian children in this age group primarily function in home and school environments.

Perhaps the most telling finding in this arena was the impact of revelation of HIV status and orphanhood to officials at local schools attended by orphanage children and no such revelation to officials at schools attended by village children. Widespread reports from orphanage children of exclusion and discrimination emanating from both teachers and students supported the connection between disclosure and stigmatization. The reticence of village children to share information about taking medicine or the reason they have missed school was based upon the real expectation of negative response from friends and teachers. The research participants who have been excluded from play may have been aware of the precipitating reason, but most have not connected the avoidant behaviors of peers with their diagnosis, and seemed to be somewhat bewildered by this

state of affairs. It is possible that because these children have been engaged in very little discussion of orphanhood or HIV infection they are without the necessary information to put the cause and effect together.

Residential placement contributes to the social experience of the HIV positive orphaned child. The environment at the orphanage has been very insulating for the resident children, offering acceptance from the staff and parity among the children. Although this has contributed to their comfort at home, there was an essential disconnect for them between their experience of themselves at home and in the world. How they negotiate this dissonance in the future will be crucial to their eventual integration into greater Tanzanian society.

The experience of village children was different. Children who did not live with a surviving parent suffered variable discriminatory responses ranging from separate eating utensils to verbal abuse by others in the home. These conditions left them feeling overworked, singled out, and isolated. The village children who lived with surviving parents shared their HIV diagnosis, which helped the children to feel some level of acceptance not enjoyed by children who live with extended family or community members. Exploration of the social experience of HIV positive family units in their communities is an investigation in need of further study. Village children who hide their orphanhood or/and HIV diagnosis in public will face many of the same challenges to acceptance and integration as they age as children living in the orphanage, although for some inverse reasons.

Sub-question 2 of this investigation asks how the children perceive what the society is telling them about their identification as orphans infected with HIV. They believed both conditions to be burdensome. In addition, the majority of the children believed that they were of diminished worth relative to their peers because of the phenomenon, as illustrated by their self-stigma. This pervasive attitude could not have developed intrinsically in all of the participants without social learning that supported orphanhood and HIV infection as negatively perceived conditions.

Some participants expressed the belief that children who are orphaned or HIV positive should treated better than they often are. Several specifically mentioned the right of all children, orphaned or not, to receive good care. Whether these beliefs are present because the children are affected by the phenomenon, or that this generation of Tanzanian children was more aware of the recent recognition of children's rights, is not known.

Qualities Used to Meet the Experience

Research participants exhibited and described a variety of personal characteristics and adaptive responses to the conditions of their lives. Some of these qualities may be cultural in nature, while others appeared to be in direct correlation to orphanhood and chronic illness. Because this study was descriptive in nature, no attempt was made to delineate or ascertain the origin of these qualities or developed mechanisms.

The majority of children in this subset of HIV positive Tanzanian orphans exhibited high levels of the qualities that support healthy emotional functioning. They recognized the challenges presented by illness, orphanhood, poverty, and social stigma, and have developed ways to minimize their effect. In this way, they have cognitively

developed ways to deal with everything from power imbalances to food scarcity. The fact that successful coping was attained through cognitive reduction of the impact of their negative experiences of the phenomenon is consistent with Folkman's (1986) definition of learned resourcefulness. And, since such learning takes place over time, the gradually accumulated experience of coping well with negative life experiences leads to increased resilience and the ability to meet new challenges with confidence. Masten (2001) believed that resilience is a process that develops with cumulative experience. The participants in this study were quite young, having recently attained what is commonly called the age of reason. Although they manifested many of the traits that will serve them well in successful coping with the challenges of orphanhood and HIV infection, these children must continue to develop the skills as they age in order to meet the social and other barriers they will encounter.

Exhibiting high levels of internality, the children in this study have learned not to rely on others to provide more than basic necessities. This does not mean that they would not welcome assistance; just that they do not expect or seek it. Some research postulates that without healthy trusting relationships in childhood there is a greater risk of anti-social behavior in adulthood (Laser & Leibowitz, 2009). However, because this was not a longitudinal study no theories were advanced about the future implications of the lack of such relationships. Instead, ways to meet the postulated needs that might have been filled by deceased parents will be discussed in the recommendations for action later in this document.

An underlying sense of hope pervaded the lives of most of these children. The basic tenets of hope theory, that the children have not only goals but also the necessary will to pursue them, were uniformly evident in the attitude of the participants toward their futures (Snyder, et al, 1991). They expected to live as productive adults, following the variable paths in family and work life demonstrated by those who have gone before. Perhaps because they are the first generation of HIV positive orphans to live long enough to have these visions, the challenges ahead of them have not yet been illuminated. However, it is equally possible that they are resilient beings who have been incrementally preparing for their adulthood, positively adapting to the phenomenon, since birth. Where hope is usually seen as the cognitive interaction between goal setting and personal agency, belief in God was also a very strong component for these children. Seeing God as an ever-available source of support and guidance, the children maintained unwavering knowledge that they can create their dreams with their own effort and determination in the presence of God.

According to various chronic disease researchers, positive adaptation to life with chronic HIV disease is an ongoing process (Charmaz, 1983; Folkman, Lazarus, & Dunkel-Schetter, 1996). Like resilience, as discussed above, this adaptation will be a cumulative process throughout the life, and disease stages, of HIV positive orphans. Even at their young ages, participants had a clear awareness and acceptance of the part medication and medical management play in the ongoing story of their life. By managing their own self-care, the village participants in particular exerted some control over the course of the illness. Eiser (2004) and Miller and Wood (1991) spoke to the positive

interactive process between chronic disease self-care and other domains of experience that are supported by this self-reliance and which will continue over the lifespan. These actions and attitudes, then, provide additional opportunities for the development of learned resourcefulness in every area of their lives.

Hildenwall (2007) believed that the local meaning and understanding of a disease affects the child's self concept. This is an important aspect of adaptation to life as an HIV positive Tanzanian child. The mechanisms for spread of HIV are widely misunderstood in Tanzanian society once sexual contact has been eliminated. Many believe that sharing food, bedding, or play can lead to infection with the virus. Thus, these children, as a new societal group, face not only the effect of the stigma toward a sexually transmitted disease but also the pervasive ignorance about the life, or threat of, a perinatally infected child.

The participants in this study have cognitively developed methods of diminishing the appearance of physical limitation upon daily activities in order to support social acceptance. This is a common strategy in Tanzanian society, as there is a very real need to work physically in order to provide materially for self or family. However, it seems that the self-stigma described by these children was derived more from the type of infection than from its manifestations or physical limitations. The counsel of Leventhal and Mora (2005) that the child's own physical experience of, conceptualization of, and goals regarding the disease are barometers of successful coping. At present, the participants seem to be incrementally learning about and managing this interaction.

However, they are still young children, and the increased intelligence and experience of age may influence the course of their emotional adaptation to life with HIV.

Revised Conceptual Framework

The revised conceptual framework derives from the findings of this investigation. Utilizing the original framework that explored the physical, intellectual, emotional, and social realms of the experience, the figure was modified to more accurately represent evidence-based conclusions about the interactive nature of the conditions, experiences, and responses that comprise the lived experience of the phenomena.

The challenges of HIV positive Tanzanian orphanhood affect all the realms of experience. It is, then, more appropriate to describe the aspects of these experiences within the domain in which they occur. For instance, the decision whether or not to disclose HIV or orphan status occurs within the social context, and therefore must be described within that context. This decision is influenced by self-stigma, an internal experience, as well as the mechanisms that are available to the individual to make the decision. The bi-directional arrows indicate the interrelated aspects of the domains of experience in which the multiple life conditions are met. The framework as a whole represents the lifeworld of the HIV positive Tanzanian orphan.

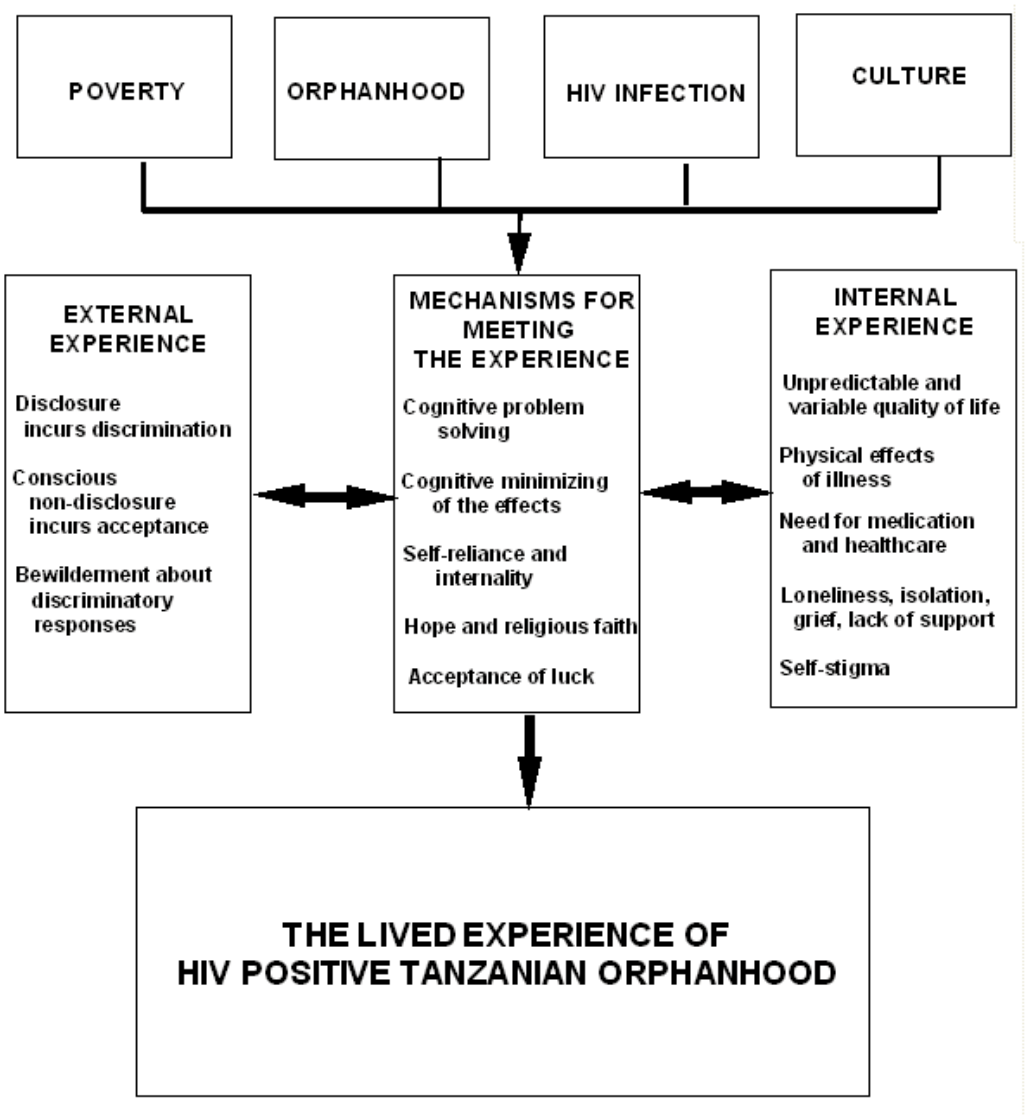

Figure 2. Revised Conceptual Framework

Recommendations for Action

Many of the qualities of the life world experienced by HIV positive Tanzanian orphans are shared by children in African and other countries with high HIV incidence. High levels of HIV stigma, large numbers of orphans, and cultural and developmental processes that inhibit rapid adaptation make the findings of this research a useful place to

begin each discussion. By incorporating what is known about the trajectory of the pandemic in each country with the realities of life on the ground, the recommendations that follow may provide guidance for development of responses in other countries in addition to Tanzania.

Many of the societal changes that are called for by the challenge of large numbers of HIV positive orphans seem to be global, but must be implemented from the bottom up rather than top down. While policy and governmental orientation to the group is important, the more crucial aspects of the social integration of these children will occur incrementally at the level of individual communication until a critical mass is obtained. One reason why the changes must be implemented at a low level is that cultural norms, although dynamic, are slow to adapt and must follow pervasive interaction with a new stressor or idea within a population. The recommendations that follow, then, will be grouped by the level at which they should be implemented. Table 2 provides an overview of recommendations for action that will be further described below.

Table 3
Recommendations for Action

Level of Implementation	Action
Individual	Support groups for HIV+ orphaned children to provide emotional support and HIV/AIDS education
Family/Caretaker	1.Support groups for caretakers to provide emotional support 2.HIV/AIDS education for caretakers: Infection control, care of HIV infected children, and "myth busting" 3.Education for caretakers on the psychosocial needs of children, particularly orphans
Community	1.Education for religious and village leaders about HIV positive orphans and childhood HIV/AIDS 2.Education for teachers and school administrators on childhood HIV/AIDS, the psychosocial needs of children, and issues of inclusion in the classroom
Non-governmental and Governmental Organization	Training, implementation and site provision for the above initiatives Policy changes that legally, financially, and socially support the rights, needs, and integration of HIV positive orphans

Individual Level

Support groups. Children who are both orphaned and HIV positive need to discuss their feelings and perceptions about living with the dual conditions in safe supportive environments with others who share these conditions. These groups will minimize isolation and allow the participants to feel both that their grief at orphanhood is

appropriate and that they are not alone in their HIV status. The children may learn strategies for meeting the challenges of many aspects of their lives through sharing. In recent years, positive outcomes on multiple levels have been enjoyed by HIV positive adult members of such groups, so it is imperative that this resource be made available to children as well.

A second level of support would come to the children if the group included a well trained HIV education. A second level of support would come to the children if the group included a well trained HIV educator. The children need to learn about HIV itself, why it is stigmatized, how to live positively in childhood and adulthood, and begin to think about how they will address marriage and possibly parenthood knowing that they are HIV positive. The participants in this study live with adults who are ill-equipped to provide this information and support, so it must be offered by another individual. As we provide sex education to American children so that they can make good decisions in the future, targeted education to HIV positive children will go a long way toward informing their choices in adulthood.

Family and Caretaker Level

Households that include an HIV positive orphaned child are often without the emotional, economic, and educational resources to meet this challenge. Several types of support are necessary to move the entire household into a positive relationship with the circumstance. This support may also assist the members of the home to acceptance as persons who are acting responsibly toward a child rather than harboring a danger to the community.

Support groups. The often female heads of household where an HIV positive orphan lives need to know that they are not alone in caring for such a child. They often feel the burdens of secrecy and shame in addition to the financial burden of feeding and caring for an orphan. Support groups for these caretakers would provide awareness that others face the same challenges, minimize shame, and could lead to shared problem solving.

Educational programming. Clinic care of HIV positive children covers only medical testing and the dispensing of medication. Caretakers of these children do not receive any education on the care of the children, signs of serious complication, or myths and realities of the risk of spread to other household members. Education of caretakers could be provided by community health workers or local NGO's once families are identified. Linkage to these services could be offered to identified households by both the HIV clinic personnel and other local resources such as village leadership.

A second educational need for caretakers of these children is knowledge about children's rights and emotional needs, and the importance of communication to support both problem solving and future planning. The children in this study expressed the wish to use adults in their homes for these purposes, but are unwilling to ask or trust that the request will be met positively. This type of child-adult interaction is not familiar to Tanzanian adults, and will need to be slowly introduced in order to minimize resistance to long-held beliefs about the role of the child in society. The goal is to provide social guidance to parentless chronically ill children so that they can best enter into society as

productive members because they have enjoyed the mentoring of responsible and responsive adults.

Community Level

The most important individuals at the community level of engagement are the community leaders, religious leaders, and school personnel. Although they come from different perspectives in their interactions with community members, these respected persons express attitudes that shape public opinion and contribute to the formation of local social processes.

Educational programming and discussion for religious and village leadership. In the recent past, formal discussions among community leaders have been helpful in deconstructing stereotypes and misinformation as well as identifying the needs of community members living with HIV/AIDS or other chronic disease. These meetings have contributed to collaboration among the various entities working in the area in attempts to create local networks and avoid duplication of services (Mwashala, personal communication, February 4, 2009). Such meetings where the needs and experiences of HIV positive orphans are the focus would begin the process of identification of families in need, recognition of the large numbers of affected children, and heightened local awareness of the problems. Village and religious leaders are in the unique position to motivate members to new ways of thinking about HIV (Beard, 2005). Hopefully, stigma reduction would also be an outcome since the general population often considers ideas expressed by their leaders as worthy of consideration.

Educational programming and discussion for school administrators and teachers.

Tanzanian teachers rarely have more than a year or 2 of post-secondary education coursework before being placed in the classroom. Principals and higher level educators may have a bachelor's degree, but little psycho-social training. A major concern of those familiar with this state of affairs is the unprofessional approach most Tanzanian teachers take toward the emotional and social health of their students, relying instead on cultural norms. Teachers may, in addition, be passing their own stigmatizing attitudes on to their students by example in the classroom. Supplementary programming for teachers and other educators on general childhood psychology and socialization would help these educators to upgrade their skills and provide a better quality educational environment to all students. This training must be delivered in a culturally appropriate way so that explorations of the benefit of changing long-held beliefs about children can be explored without fear or discomfort.

A secondary topic of the training would be the importance of leadership by teachers on issues of inclusion. Not all Tanzanian teachers have been well educated about HIV, yet can be an important source of information to students. Students mimic the behavior and attitudes of their teachers toward fellow students, so an accepting attitude toward orphans and HIV positive children as modeled by teachers would facilitate the integration of these children into their peer group. Also, since teachers were viewed by the study participants as adults whom they might approach for help or problem solving, teachers must be educated to realize the important role they can play in the formation of the character of their students.

Non-Governmental and Governmental Organization Level

NGO's and government agencies working on social and health issues are in the ideal position to support the above initiatives. Both types of organizations can provide training sites and trainers and develop curricula and processes to begin the work of awareness and integration of HIV positive orphans into the wider society. Although the topic area is new, it follows the work that has already begun on HIV awareness and stigma reduction. The difference here is that there is no one to speak for the needs of these children, and policy makers must begin to be aware of the long term ramifications to the entire Tanzanian society of ignoring them (Ndosi, personal communication, October 12, 2008).

Policy is the arena in which the movement from the bottom up can be formalized. In 2005, when antiretroviral drugs first became available to HIV positive Tanzanians, 10% of the supply was earmarked for children under 15 years of age (UNICEF, 2006). Some researchers estimate that at least 12% of new cases of HIV in the world each year will be children, which will affect that plan dramatically in the years ahead (Alvarez & Rathore, 2007). In addition, with an increasingly young population, medication and service provision to HIV positive Tanzanian children will call for increasing federal budgetary distributions and attention. HIV /AIDS has been recognized as a development issue, and the integration of hundreds of thousands of parentless HIV positive young people into the society will, of necessity, have an effect upon the development of Tanzania. In addition, Tanzania's relatively recent agreement to sign the African Charter on the Rights of the Child signals early readiness to engage in the creation of policy that

supports the terms of the Charter. With integrated effort at all levels of society, inclusion and recognition of the innate dignity that is the right of all citizens can be attained for HIV positive orphans.

Implications for Social Change

Tanzanian society has been responding to the impact of HIV since the late 1980's. Much progress has been made in raising awareness of modes of infection, treatment options, the presence of infected persons in all social classes and groups, as well as the large numbers of AIDS orphans. The emergence of a new social group, medically stable HIV infected orphaned children, is a new challenge to existing beliefs and responses in the fight against HIV/AIDS. This study has uncovered the qualities of the experience of the phenomenon for members of the group and revealed gaps and necessary changes that invite action by communities and the wider society. The implications for social change of this study will be discussed in terms of the individuals experiencing the phenomenon, the communities in which they live, and society as a whole.

Individuals

While conducting the interviews, this researcher was surprised by the ease with which the participants shared their beliefs and perceptions about their lives. This was probably a product of both trust engendered by the interview process as well as the wishes of the children to have their voices heard. Time and again participants begged the research assistant and me to ask more questions because they were hungry to talk more about their lives. Perhaps because we were not actively involved in their day to day lives, we could be used as vehicles for expression without consequence. Observing this state of

affairs, it became clear that one of the needs of these children is the opportunity to talk about how they feel about life as HIV positive orphans.

Traditionally, Tanzanian children are viewed as supportive to the economic life of the family, and their input is rarely sought on any issue. Respect for elders is a universal expectation. There is, however, a very recent recognition in Tanzanian social service and human rights circles that children are deserving of respect, and that children who feel they, their ideas, and feelings are valued often become more productive adults (Laser & Leibowitz, 2009). The openness of the participants and their revelation of the impact of the silence surrounding their life condition shines a light on the need for processes that both allow the children to speak, and elders in their world to listen.

The change in communication with members of this societal group called for by this research may contribute to changes in the social world of all Tanzanian children, not just HIV positive orphans. As the rights of women have increasingly become part of national, and in fact international, dialogues, societies have opened to and become richer through fuller participation by women. This researcher believes that HIV positive orphans can teach us much about how best to support this group's integration into wider Tanzanian society. The direct results to the children will be minimization of the isolation and discrimination they endure, as the listeners begin to understand and respond in ways that may extend into all settings and institutions.

Communities

Communities often continue about their work until it becomes necessary to respond to a new stressor or condition. The identification of hundreds of thousands of Tanzanian

orphans living with extended families or guardians led to changes in how families were defined and questions about how neighbors, schools, and other entities might help each other in dealing with this economic and social crisis. These communities now face an additional layer of complexity, in that some of the orphans are not only HIV positive, but with good medical management can be expected to live into adulthood. Until 2005, few of these children were expected to survive past their fifth birthday (Brahmbhatt, et. al 2006). Guardians who knew little about HIV but were aware of the HIV status of the orphans in their care continued to hide this fact for fear of stigmatizing response toward the entire family from neighbors. They have observed the very slow recognition of HIV positive adults in their midst, and are unwilling to bring shame upon their own households. Herein lies a possibility for attitudinal change that will have positive effect on acceptance of the diversity of community members. Perhaps the most important fact in the possibility of a move toward acceptance of HIV positive orphans is recognition that these victims are blameless. They have neither engaged in risky sex, nor made poor choices that led to their orphanhood. Thus, if there is no blame to be placed, there is room for communities to begin, through dialogue, to formulate a new definition of what it means to be HIV positive. Then families and guardians of HIV positive orphans can live with openness again, and HIV positive persons can be seen as living with a chronic, but manageable, illness. Such a process at the local level can ultimately translate to the wider society.

Society

Tanzania has a very young population, with nearly ½ of the residents under 20 years of age (UNICEF, 2006). The impact of hundreds of thousands of parentless HIV infected young people upon the society in which they live is clearly in need of consideration. This is not a temporary situation, since the rate of perinatal HIV infection continues unabated while more HIV infected young women come into their child bearing years. Because of the availability of antiretroviral drugs, the raw numbers of young persons living with HIV is expected to continue growing, increasing their proportionate numbers in the overall population (Bendavid & Bhattacharya, 2009). This state of affairs is not limited to Tanzania, but is also present in other African and low resource countries with similar disease trajectories and populations.

Economic, social, and behavioral stressors to Tanzanian society because of the above situation are just becoming visible. The society will have large numbers of persons who are in need of targeted healthcare support during their entire lifespan. Many of the HIV positive children who are beginning to reach puberty have not received the all important information about HIV prevention when it is they who are the vector for spread of the disease. In some cases this is because of the early death of parents who might have been in the educational role. In addition, governmental and NGO responses to the non-medical needs of HIV positive children and adolescents are clearly absent. Even now, there are anecdotal accounts that, for some HIV positive young people with or without family, personal and public expectations about normal family life take precedence over informed decision making about marriage and procreation. Functioning in a society

where HIV infection leads to stigmatization, it is no wonder that they keep their status a secret by following cultural norms for family building.

In addition to the challenges of HIV, the research in countries with large numbers of orphans point to the society-wide problems associated with improper socialization and education of these children. The fear is that great numbers of young adults without appropriate skills may lead to losses in the fragile national gains in development. The first purpose of this investigation has been to shine a light on a brewing problem that will be facing civil societies throughout the developing world. Societal responses will need to be tailored to fit both those environments and the scope of the challenges posed by the phenomenon within them. The revelations of the lifeworld of the research participants begin to give Tanzanian society a place to start in the social integration of HIV positive children, both orphaned and not, as well as development of responses that will benefit the society as a whole.

Dissemination of Results

Community partners that participated in this research are anxious to hear the results. They, like other local organizations and NGO's, have recently become aware that there may be large numbers of HIV positive orphans living in their service areas (Mawere, personal communication, May 5, 2008). The first entities with which the results will be shared are community organizations, including schools and village leadership, in the study area. The results will also be shared with the Arusha and Arumeru District Medical Officers, the Arumeru District Commissioner, the Tanzanian Minister of Health and Social Welfare, as well as TACAIDS, the Tanzanian HIV/AIDS authority. Following

discussions on the results and recommendations for action in the Arusha environs, contact will be made with other such organizations throughout Tanzania to begin sharing the results countrywide.

The guardians of the participants will receive, if they wish, a report of the findings about the group but, for reasons of confidentiality, not individual participants. This can be supplied in a private meeting or written form, as they prefer. It is expected that these meetings will engender further discussions based upon the findings and may lead to further research.

Beyond the borders of Tanzania, the results of this research will be shared with those working with HIV affected populations throughout the world. The fate and challenge of HIV positive orphaned children is a new, and largely unrecognized, source of concern for all countries with high burdens of HIV. Publication of the results in journals and presentation at international forums such as the International AIDS Conference will help in dissemination of the results and engender further research and development of strategies to meet the challenge.

Recommendations for Further Study

This research began the conversation about the lifeworld of HIV positive Tanzanian orphans and the impact this group will have upon Tanzanian society. The findings, as well as the data collection process, revealed unexplored, but important areas for futher investigation. Two major areas for further study derive from findings. The first is a set of questions about the social integration and adaptation of the children by place of

residence and over time, and the second is about certain aspects of the experience for village families.

The children living at St Lucia Nursing Home and Orphanage reported discriminatory responses from community members who knew that they were HIV positive and orphaned. This finding brings up questions about the impact of revelation of HIV status on the social integration of children so described, the effect of revelation on peer interactions, and the social impact of institutional placement of HIV positive orphans. A longitudinal study of the described children from both settings would contribute to understanding the differential levels of adaptation and integration of the phenomenon over time. In addition, a longitudinal study would provide clues to the interaction between the course of the chronic illness and social integration. Further study on the gender differences in these experiences might provide additional clues to the course of such interactions.

A second area for further inquiry is the source of the coping mechanisms and intrinsic factors HIV positive Tanzanian orphans use to meet the life experience of the phenomenon. It is unclear whether their resilient responses are a natural outgrowth of cultural expectations in situ for how to deal with problems, or a developed and intrinsic skill set that has its basis in learned responses to the phenomenon. Thus, the investigation would reveal whether resilience is the norm in the context of East Africa, or if the healthy responses are, in fact, directly related to the phenomenon at issue.

The findings uncovered about the experience of children and families living in the villages pose some unanswered questions. First, it is unclear whether the degree of food

insecurity and variable quality of life experienced by the participants living in the villages is the norm for poor Tanzanian village families with children or a direct result of the addition of an HIV infected orphan to the household. The impact of additional children or family members upon economic resources in any home is clear. However, whether there is a specific correlation to the addition of a parentless child with chronic disease is unknown.

To date, much research has been performed to reveal the impact of HIV status upon the inclusion or discrimination of infected individuals in village settings (Campbell, Nair, Maime, & Nicholson, 2007; Crampin, et al., 2007; Dlamini et al., 2007, Varga et al., 2006). However, the revelation that there are households where not only one, but all members, are HIV positive opens the door to questions about how these whole families are received in their home villages. In addition, there are questions about the relative adaptation of children living with HIV who's parents are also infected to those who are the only identificed patient in a household. Revelation of different mechanisms for dealing with these life conditions may point toward new ways to address the phenomenon.

Personal Reflections

While formulating the scope of a study and developing interview questions, it is easy for a researcher to believe that they know what questions they are looking to answer. As I worked through this process, the abiding question in my mind was "what is it like to be a Tanzanian child who is both an orphan and HIV positive"? Yet when I looked at the variability of experience that might comprise the answer, it was difficult to winnow all

the possible aspects to those that I could reasonably expect to be able to describe. I realized I could only set the stage and then see what data appeared. In addition, it was clear that the phenomenological investigation required bracketing of my own beliefs about children, since I am a mother couched in American ideas on childrearing, and academically grounded in theories about the interactions among members of society. The call of this project, then, was to set aside those judgements and that education, and return to what has been called “child mind”, or suppositionless learning where all that presents itself is new, and also true.

My first opportunity to do this presented itself when I received the English language transcripts of the first set of interviews. After more than a year of living with the inquiry and thinking that my research design was a good one, I excitedly began to read the trasncripts. I was deeply disappointed. Answers to interview questions seemed incomplete. The interviewer did not ask follow up questions that came to my mind, and I felt the moment had been lost. Because I was unsure how I might address these problems, I decided to continue the interviews as designed and do the best I could with the data generated. I was forced not only to surrender and bracket what I thought I knew about the subject and the participants, but also to trust the process.

A second pass through the transcripts felt better. Creating the code book, and marking the transcripts with the codes, increased my ability to see what was really there. Soon I was finding what Van Manen (1990) called “clusters of meaning” in every sentence. Although I deeply respect the knowledge we have gained from quantitative research, I believe the human condition can best be explored qualitatively. For this is the

lesson of phenomenology: that the words, drawings, and gestures of the participants speak for themselves. What emerged was a set of data that told me everything the children wanted me to know. My job was to just to listen. We often say that children are innocent, and it was from their innocence that I was able to learn how to reclaim my own in data analysis. Their voices were the only truth, and the more I worked with the data, the less I was present in it. After several months of "living" the data, I was finally able to organize and distill the essence of their experience. I have learned that research is a process that has it's own map, and it is the scholar's job to follow it.

Here is what I have learned. HIV positive Tanzanian orphans are children like any others. They want to be taken care of and loved. They want to play, learn, and plan for a bright future. And even in the face of burdens that would reduce most of us to depression and worse, they remain joyful and resourceful. They deserve our support and respect, for if their country or others do not provide that, we have given up our right to expect them to be good citizens of the world.

I feel priviledged to have become intimate with these children. Hopefully, the participants of this inquiry have felt empowered by the fact that someone, even a *mzungu* (foreigner), wanted to know how they felt, and was willing to ask and listen. They have taught me what resilience really means, and the power that is inately available to most of us, if we choose to access it.

Summary

There are risks to any country that does not respond to the provocation of HIV infected orphans within their midst. Without awareness of the phenomenon, and good

programming to meet it, the increasing proportion of HIV positive young people in already young demographics could have disastrous effect upon their societies (Pendergast et al., 2007). There are reports throughout Africa of orphaned children, rootless and disconnected, who operate on the fringes of society (Strydom & Raath, 2005). When HIV infection from birth is added to the burdens many of them carry, the phenomenon can be devastating to the developing countries in which they live, let alone to the young people themselves.

Whether Tanzania is prepared or not, there will be a system-wide impact from the hundreds of thousands of HIV infected orphaned children who have already been born, as well as those to come. How the challenge is framed will be important. If viewed as a threat to the status quo, the phenomenon of HIV positive orphanhood will be divisive. If viewed as an opportunity, a new definition of HIV positive could allow infected persons of all ages to more fully engage in the growth and prosperity of their country. By beginning to understand the lifeworld of these children, and building upon previous research about the impact of orphanhood and the experiences of adults living with HIV, leaders have the opportunity to formulate responses that benefit everyone. It is hoped that this research will provide some guidance to support the future of the nation and the children like those who have been the inspiration for this research.

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APPENDIX A
CONSENT FORMS

CONSENT FORM FOR VILLAGE CHILDREN

Hello, I am Elizabeth Nguma. Carol Parker from America is doing a project to learn about the life of Tanzanian children like yours. She has asked me to invite _____ to join her project. She has picked the child for this project because he/she is between 9-12 years old, one or both of their parents have died, and they are HIV positive. I am going to read this form with you. You can ask any questions you have before you decide if you want this child to be in the project.

WHO WE ARE:

Carol Parker is studying for an advanced degree at Walden University in America. I am working with her to talk to children in Swahili about their lives so that she can learn about Tanzanian children like yours. You may have heard that Carol Parker from the _____Project visits with _____leaders. However, she wants you to decide for yourself if you are interested in being part of the project, and wants you to know that nothing will change at _____no matter what you decide.

ABOUT THE PROJECT:

If you agree that your child may join this project, they will be asked to:

1) Meet 2 or 3 times for about 1 hour each time to talk with me, draw pictures, and do other things like that.

2) We will schedule the meetings with you and they will all be finished within 2 weeks time from the first meeting to the last.

3) We will meet privately at your home or somewhere else that no one but you, me and your child will know about.

The questions we will ask your child are to learn about what they are thinking, not to treat them like a counselor or a doctor might. We want to know how they feel about being at school, going to the clinic, having friends and things like that. When we ask many children the same set of questions we call that research, which means we learn very important things from the information that the children share with us. It is not to help them with their problems, but to learn what they might need so that others can offer help or treatment in the future.

I will be making audio tape recordings of our conversations so that I can remember everything that the child says, but the tapes will be locked up so no one who shouldn't hear them will be able to. The tapes will never be heard by anyone other than the researchers, and the researchers will never use the information about you for any purpose except this particular research. The information we learn about Tanzanian children like yours might be reported to other professionals, but those people will never know who you are or hear the tape recordings.

IT'S YOUR CHOICE:

Volunteering means that you freely decide that you want your child to be part of this research. You might decide to volunteer because you see that children like yours should be able to speak about the challenges they face in their lives.

You don't have to join this project if you don't want to. You won't get into trouble with me, _____, or anyone else if you say no. If you decide now that you want to join the project, you can still change your mind later just by telling me. If you want to skip some parts of the project, you can just let me know.

It's possible that being in this project might take some time for the child from doing other things, or maybe make them have some uncomfortable feelings. For instance, if we talk about their parents who are gone, they might become sad. But this project might help other children who have been through many of the experiences that this child has, if you agree that the child may lift their voice. In fact, it is important that adults know what children are thinking and what they need in their lives so that we can help them. Some adults in Tanzania really want to help children like yours and their families, but we need to know what the children think before we begin. If you or the child want counseling for these feelings that might come up during the interviews, we will provide a trained counselor free of charge to you.

If you choose to join this project, the child and I will have snacks together and they may keep the art supplies we use after we have finished. Also, if you choose to join we will pay all of the child's travel expenses and give your family some compensation for your and the child's time to say "thank you" after we have finished the meetings. If you decide not to have your child finish all of the interviews, or withdraw from the research at any time for any reason, you will still receive the compensation for the travel that was completed and the percentage of the meetings that they did finish.

PRIVACY:

Everything you and the child tell me during this project will be kept private. That means that no one else except you, me and the research team will know your name or what answers the child gave. Remember, the information we learn about Tanzanian children like yours might be reported to other professionals, but those people will never know who you are or hear the tape recordings. The only time I have to tell someone is if I learn about something that could hurt the child, you or someone else.

ASKING QUESTIONS:

You can ask me any questions you want now. If you think of a question later, you can reach me at 0748212380. If you have questions you would like to ask of another person who can help you to decide about participating, you may call Aziz Suleiman at 5764929326. He works at Mkombozi Children's Organization, has done research of this type, but is not part of this research team and is there just for you. I will come back tomorrow after you have had time to think and talk with your family to see what you have decided. Remember, you can say no, and everything will be fine.

I will give you a copy of this form.

Please sign your name below if you agree to consent for your child to join this project.

Guardian
Witnessed_____
_____

CONSENT FORM FOR ORPHANAGE CHILDREN

Hello, I am Elizabeth Nguma. Carol Parker from America is doing a project to learn about the life of Tanzanian children like those living at _____. She has asked me to invite _____ to join her project. She has picked the child for this project because he/she is between 9-12 years old, one or both of their parents have died, and they are HIV positive. I am going to read this form with you. You can ask any questions you have before you decide if you want this child to be in the project.

WHO WE ARE:

Carol Parker is studying for an advanced degree at Walden University in America. I am working with her to talk to children in Swahili about their lives so that she can learn about Tanzanian children like those living at _____. You may have heard that Carol Parker from the _____Project visits with _____ leaders. However, she wants you and the child to decide for yourselves if you are interested in being part of the project, and wants you to know that nothing will change at _____no matter what you decide.

ABOUT THE PROJECT:

If you agree that the child in your care may join this project, they will be asked to:

1) Meet 2 or 3 times for about 1 hour each time to talk with me, draw pictures, and do other things like that.

2) We will schedule the meetings with you and they will all be finished within 2 weeks time from the first meeting to the last.

3) We will meet privately at _____ or somewhere else that no one but you, me and the child will know about.

The questions we will ask your child are to learn about what they are thinking, not to treat them like a counselor or a doctor might. We want to know how they feel about being at school, going to the clinic, having friends and things like that. When we ask many children the same set of questions we call that research, which means we learn very important things from the information that the children share with us. It is not to help them with their problems, but to learn what they might need so that others can offer help or treatment in the future.

I will be making audio tape recordings of our conversations so that I can remember everything that the child says, but the tapes will be locked up so no one who shouldn't hear them will be able to. The tapes will never be heard by anyone other than the researchers, and the researchers will never use the information about you or the child for any purpose except this particular research. The information we learn about Tanzanian children like yours might be reported to other professionals, but those people will never know who you are or hear the tape recordings.

IT'S YOUR CHOICE:
Volunteering means that you freely decide that you want your child to be part of this research. You might decide to volunteer because you see that children like yours should be able to speak about the challenges they face in their lives.
You don't have to join this project if you don't want to. You won't get into trouble with me, _____, _____, or anyone else if you say no. If you decide now that you want to join the project, you can still change your mind later just by telling me. If you want to skip some parts of the project, you can just let me know.
It's possible that being in this project might take some time for the child from doing other things, or maybe make them have some uncomfortable feelings. For instance, if we talk about their parents who are gone, they might become sad. But this project might help other children who have been through many of the experiences that this child has, if you agree that the child may lift their voice. In fact, it is important that adults know what children are thinking and what they need in their lives so that we can help them. Some adults in Tanzania really want to help children like yours and their families, but we need to know what the children think before we begin. If you think the child needs some counseling for these feelings that might come up during the interviews, we will provide a trained counselor free of charge.
If you choose to join this project, the child and I will have snacks together and they may keep the art supplies we use after we have finished. Also, if you choose to join we will pay all of the child's travel expenses and give the child a t shirt or something like that as compensation for your and the child's time to say "thank you" after we have finished the meetings. If you decide not to finish all of the interviews, or withdraw from the research at any time for any reason, the child will still receive the compensation for the travel that was completed and the percentage of the meetings that they did finish

PRIVACY:
Everything you and the child tell me during this project will be kept private. That means that no one else except you, me and the research team will know your name or what answers the child gave. The only time I have to tell someone is if I learn about something that could hurt the child, you or someone else. Remember, the information we learn about Tanzanian children like yours might be reported to other professionals, but those people will never know who you are or hear the tape recordings.

ASKING QUESTIONS:
You can ask me any questions you want now. If you think of a question later, you can reach me at 0784212380. If you have questions you would like to ask of another person who can help you to decide about participating, you may call Aziz Suleiman at 5764929326. He works at Mkombozi Children's Organization, has done research of this type, but is not part of this research team and is there just for you. I will come back tomorrow after you have had time to think and talk together privately to see what you have decided. Remember, you can say no, and everything will be fine.

I will give you a copy of this form.

Please sign your name below if you agree to consent for your child to join this project.

_____

Guardian

ASSENT FORM FOR VILLAGE CHILDREN

Hello, I am Elizabeth Nguma. A researcher from America is doing a project to learn about the life of Tanzanian children like you. She has asked me to invite you to join her project. You have been picked for this project because you are between 9-12 years old, one or both of your parents have died, and you are HIV positive. I am going to read this form with you. You can ask any questions you have before you decide if you want to do this project.

WHO WE ARE:

Carol Parker is studying for an advanced degree at Walden University in America. I am working with her to talk to children in Swahili about their lives so that she can learn about you and other Tanzanian children. You may have heard that Carol Parker from the _____Project visits with _____leaders. However, she wants you to decide for yourself if you are interested in being part of the project, and wants you to know that nothing will change at_____ no matter what you decide.

ABOUT THE PROJECT:

If you agree to join this project, you will be asked to:

- Meet 2 or 3 times for about 1 hour each time to talk with me, draw pictures, and do other things like that.

- We will meet privately at your home or somewhere else that no one but you, me and your guardian will know about.

- We will schedule the meetings with you and your guardian and they will all be finished within 2 weeks time from the first meeting to the last.

The questions we will ask you are to learn about what you are thinking, not to treat you like a counselor or a doctor might. We want to know how you feel about being at school, going to the clinic, having friends and things like that. When we ask many children the same set of questions we call that research, which means we learn very important things from the information that the children share with us. We are not talking with you to help you with your problems, but to learn what help you and other children like you might need so that other adults can offer help or treatment in the future.

I will be making audio tape recordings of our conversations so that I can remember everything that you say, but the tapes will be locked up so no one who shouldn't hear them will be able to. The tapes will never be heard by anyone other than the researchers, and the researchers will never use the information about you for any purpose except this particular research.

IT'S YOUR CHOICE:

Volunteering means that you freely decide that you want to be part of this research. You might decide to volunteer because you see that children like you should be able to speak about the challenges they face in their lives.

You don't have to join this project if you don't want to. You won't get into trouble with me, _____, your caretaker, or anyone else if you say no. If you decide now that you want to join the project, you can still change your mind later just by telling me. If you want to skip some parts of the project, you can just let me know.

It's possible that being in this project might take some time from doing other things, or maybe make you have some uncomfortable feelings. For instance, if we talk about your parents, you might become sad. But this project might help other children who have been through many of the experiences that you have, if you can lift your voice. In fact, it is important that adults know what children are thinking and what they need in their lives so that we can help them. If you and your guardian think you need some counseling for these feelings that might come up during the interviews, we will provide a trained counselor free of charge.

If you choose to join this project, we will have snacks together and you may keep the art supplies we use after we have finished. Also, if you choose to join we will pay for your transport and give your family something like some food to say "thank you" after we have finished the meetings. If you decide not to finish all of the interviews, or withdraw from the research at any time for any reason, you and your family will still receive the compensation for the travel that was completed and the percentage of the meetings that you did finish.

PRIVACY:

Everything you tell me during this project will be kept private. That means that no one else except you, me and the head researcher will know your name or what answers you gave. The information we learn about Tanzanian children like you might be reported to other professionals, but those people will never know who you are or hear the tape recordings. The only time I have to tell someone is if I learn about something that could hurt you or someone else.

ASKING QUESTIONS:

You can ask me any questions you want now. If you think of a question later, you or your guardian can reach me at 0784212380.

If you or your guardian have questions you would like to ask of another person who can help you to decide about participating, you may call Aziz Suleiman at 5764929326. He works at Mkombozi Children's Organization, has done research of this type, but is not part of this research team and is there just for you. I will come back tomorrow after you have had time to think and talk with your family to see what you have decided. Remember, you can say no, and everything will be fine. I will give you a copy of this form.

Please sign your name below if you want to join this project.

Name of Child _____

Child Signature (or witnessed verbal consent) _____

Parent/Guardian Signature (or witnessed verbal consent) _____

Witness _____

ASSENT FORM FOR ORPHANAGE CHILDREN

Hello, I am Elizabeth Nguma. A researcher from America is doing a project to learn about the life of Tanzanian children like you. She has asked me to invite you to join her project. You have been picked for this project because you are between 9-12 years old, one or both of your parents have died, and you are HIV positive. I am going to read this form with you. You can ask any questions you have before you decide if you want to do this project.

WHO WE ARE:

Carol Parker is studying for an advanced degree at Walden University in America. I am working with her to talk to children in Swahili about their lives so that she can learn about you and other Tanzanian children. You may have heard that Carol Parker from the Pamoja Project visits with _____leaders. However, she wants you to decide for yourself if you are interested in being part of the project, and wants you to know that nothing will change at _____ no matter what you decide.

ABOUT THE PROJECT:

If you agree to join this project, you will be asked to:

1) Meet 2 or 3 times for about 1 hour each time to talk with me, draw pictures, and do other things like that.

2) We will meet privately at St Lucia or somewhere else that no one but you, me and your guardian will know about.

3) We will schedule the meetings with you and your guardian and they will all be finished within 2 weeks time from the first meeting to the last.

The questions we will ask you are to learn about what you are thinking, not to treat you like a counselor or a doctor might. We want to know how you feel about being at school, going to the clinic, having friends and things like that. When we ask many children the same set of questions we call that research, which means we learn very important things from the information that the children share with us. We are not talking to you to help you with your problems, but to learn what help you and other children like you might need so that other adults can offer help or treatment in the future.

I will be making audio tape recordings of our conversations so that I can remember everything that you say, but the tapes will be locked up so no one who shouldn't hear them will be able to. The tapes will never be heard by anyone other than the researchers, and the researchers will never use the information about you for any purpose except this particular research. The information we learn about Tanzanian children like you might be reported to other professionals, but those people will never know who you are or hear the tape recordings.

IT'S YOUR CHOICE:
Volunteering means that you freely decide that you want to be part of this research. You might decide to volunteer because you see that children like you should be able to speak about the challenges they face in their lives.
You don't have to join this project if you don't want to. You won't get into trouble with me, _____, or anyone else if you say no. If you decide now that you want to join the project, you can still change your mind later just by telling me. If you want to skip some parts of the project, you can just let me know.
It's possible that being in this project might take some time from doing other things, or maybe make you have some uncomfortable feelings. For instance, if we talk about your parents, you might become sad. But this project might help other children who have been through many of the experiences that you have, if you can lift your voice. In fact, it is important that adults know what children are thinking and what they need in their lives so that we can help them. If you or your counselor or guardian think you want or need some counseling for these feelings that might come up during the interviews, we will provide a trained counselor free of charge.
If you choose to join this project, we will have snacks together and you may keep the art supplies we use after we have finished. Also, if you choose to join we will pay for your transport and give you a t shirt or something like that to say "thank you" after we have finished the meetings. If you decide not to finish all of the interviews, or withdraw from the research at any time for any reason, you will still receive the compensation for the travel that was completed and the percentage of the meetings that you did finish.

PRIVACY:
Everything you tell me during this project will be kept private. That means that no one else except you, me and the head researcher will know your name or what answers you gave. Remember, the information we learn about Tanzanian children like you might be reported to other professionals, but those people will never know who you are or hear the tape recordings. The only time I have to tell someone is if I learn about something that could hurt you or someone else.

ASKING QUESTIONS:
You can ask me any questions you want now. If you think of a question later, you or your guardian can reach me at 0784212380.
If you have questions you would like to ask of another person who can help you to decide about participating, you may call Aziz Suleiman at 5764929326. He works at Mkombozi Children's Organization, has done research of this type, but is not part of this research team and is there just for you. I will come back tomorrow after you have had time to think and talk with your counselor to see what you have decided. Remember, you can say no, and everything will be fine.
I will give you a copy of this form.

Please sign your name below if you want to join this project.

Name of Child _____

Child Signature (or witnessed verbal consent) _____

Counselor/Guardian Signature (or witnessed verbal consent) _____

APPENDIX B

LETTER OF SUPPORT

Walden University

Internal Review Board

17/5/08

Re: Lived Experience of HIV and Tanzanian Orphans.

My names are Steven D. Ndosi and I work as a volunteer with WAMATA, an organization that struggles against HIV Aids in Tanzania, as a Regional Secretary for Arusha region. I am also employed by MS-Training Center for Development Cooperation (MS-TCDC) in Arusha Tanzania as a trainer and head of Cross-Cultural Communication Department.

Carol Parker from your university has asked me to write to you about her research which aim at helping children and their guardians to express their feelings about being HIV positive. This information will eventually help her write and compile a research on Lived Experience of HIV and Tanzanian orphans.

I am writing to assure her and your Board that this work would not affect or violate in one way or another the rights of children (living with HIV) in Tanzania for the following reasons:

- I have been working as a child rights advocacy trainer/coordinator for almost ten years in Tanzania and have realized that very little has been documented on child rights situation in Africa. It is even worse with those children who are living with HIV Aids who are somehow very isolated or stigmatized by other children and the society in general. The reason for them to suffer stigma from others is basically due to lack of adequate understanding of HIV Aids and how it is transmitted. I very much believe that this research, which is to be carried out by Carol Parker, after its completion will put in the open a lot of issues which are not known by the society and eventually children and other members of the society will expand their knowledge of the pandemic and be more active and aggressive in fighting it.
- According to various researches that have been done about HIV Aids, it is believed that there are over 2.0 million children who are already infected in Africa. My belief is that there could be more other millions who are infected but are not documented. Researches that are conducted, I presume have not incorporated enough ideas and experiences of children. Had researchers involved children enough the number of the infected would have been higher. More people especially children could be dying because assistance that is availed to infected children is less than what should be there due to unrealistic statistics. I therefore strongly believe that the information to be collected from HIV positive children by Carol Parker will help identify more people who are infected.

- Many guardians and parents/grandparents, who take care of the already HIV Aids infected children do it with a lot of hardships, which are related to poor understanding of the way, the disease is transmitted. If such caretakers are involved in providing information to the researcher that information will later help them know how to take care of themselves when caring for the infected children.
- I would suggest that such guardians could be supported by providing them with an assistance such as money or food items to support them and the infected children and they should know that such support is basically due to their provision of that information.

In order not to violate the rights of the children, I propose to Carol that she should be careful by going through the right channels with enough mandate with children before starting the research. She should contact people to do interviews who are used to children or rather working with such children who are already infected. I recommend WAMATA as an organization that has been very close to children. One condition to work with WAMATA children could be to use that research to improve its (WAMATA) work and the situation of the children.

If the information from children is solely used for the intended purpose and remain confidential between the researcher and information provider, I believe the rights of children will not have been jeopardized. In addition, I propose names of children who are going to be involved in the research should not be exposed to anybody for any reason unless children themselves are willing to do so. Neighbors of children and or any other individuals shall not have any right to know what has been discussed between the researcher and children involved.

It is my belief that after the completion of this research, many people who are involved in struggle against HIV Aids will have added their knowledge of dealing with the pandemic.

I therefore recommend that Carol Parker be given all blessings to conduct a research on Lived Experience of HIV Aids and Tanzanian Orphans and that the research would not affect or violate the rights of children in Tanzania.

Steven David Ndosi
WAMATA Arusha/MS-TCDC, Arusha

APPENDIX C

INTERVIEWER TRAINING GUIDE

UN Convention on the Rights of the Child
African Charter on the Rights and Welfare of the Child
Overview of Child Development
Facilitation and Communication Skills
Mock Interview (2)
Questions and Answers

Some of the following information was taken with public domain permission from the South African AIDS Trust document *Guidelines for Working with Children who are Infected With HIV or Affected by HIV and AIDS* (2003).

It is the adult's job to help the child overcome barriers to communicating freely. As a starting point, you need to meet children **on their level**. This involves using creative and non-threatening methods to explore sensitive issues and helping children to express their feelings. Following are some examples of appropriate tools.

Drawing. Drawing can be a powerful activity for opening "hidden cupboards" in a child's life. Drawing enables children to communicate their emotional state without having to put it into words. Most children enjoy drawing, and it is a useful and practical tool during interviews.
When using drawing as a tool, it is helpful to:
-Give the child different materials to use, such as pens and markers, or paints
-Ask the child to draw something related to what you would like them to explore. For example ask them to "draw a picture of your family having fun".
-Gently follow up by asking children to describe what is happening in their drawing.
-Use open questions to encourage them to talk more about what they have drawn and why.

Storytelling. Children tend not to like lots of direct questions or long lectures. When they are finding it difficult to talk about painful issues, listening to a story about someone in a similar position can be very comforting. It can give children the sense of being understood, and it can help them to recognize that they are not alone.
When using storytelling as a tool it is helpful to:
-Use a familiar story, fable, or folktale, to convey a message, or one using animals instead of humans
-Avoid using real names or events
-At the end of the story encourage the child to talk about what happened.
-If helpful, as the children to make up their own story, based on a topic you give them. For example, "tell me a story about a little girl who was very sad".

Play. Adults often think play serves no serious purpose. Nevertheless, play is an important way that children explore their feelings about events and make sense of the world. When children play, much of their activity involves imitation or acting out-which helps us to begin to understand what type of emotions they are experiencing.
-Using everyday objects and toys, ask the child to show you parts of their life using the materials. While the child is using the objects, you can ask them what is happening.
-If the child gets stuck and cannot proceed further, ask him or her questions such as "what is going to happen next?" or "tell me about this person". Such questions can help them to continue.

NOTE It is vital that you are honest with yourself about your own feelings. These might include doubts about the HIV status of friends, or concerns about working with children facing death, or in bereavement.
You need to be aware of your own opinions about and reactions to the cultural, traditional, religious, and gender norms that influence you, as well as the children with HIV. It is vital for this research that you put all your own beliefs, feelings, fears, and judgments away so that we can collect the children's beliefs, feelings and fears and judgments only.

Joining with Children

The best way to talk with children is to form a good relationship with them from the very beginning. This is often called "joining". It includes greeting the children and talking about something that is easy for them to discuss with you. As you talk together, they can get to know you and decide whether they are comfortable with you. Some examples of how to join with children of different ages include:
For children up to 6 years: Get down on the floor with them and find a game they like to play.

For children of 6-12 years: Find a fun, relaxing activity to do together with them, such as discussing a magazine or an interesting object.

For children 13-18: Find out about their interests, such as sports or music, and ask them about their likes and dislikes.

Preparation

-Create a welcoming environment.
-Continually acknowledge and validate what the children feel and say about their situation.
-Observe what the children do as well as say. For example, note, and write down, what their body language and eye contact tell you.
-Be prepared to recognize the signs that the child needs a break. Have snacks ready, and tension breaking activities, such as a few stretching exercises or a silly song. Take a break if:

1. The child's attention is wandering.
2. They begin to squirm, or seem uncomfortable with the line of questioning.
3. They seem to become sad, or pull away in some way.

Revelation of Abuse or Neglect

It is possible that you will hear information from the child that might be considered abuse or neglect by the child's caretaker, neighbors, family members, teacher, or others living in the house. DO NOT EMOTIONALLY REACT. Just say something that acknowledges that you have heard the child. Say something like, " Wow, that is really (hard, bad, difficult) for you." Your role is just to collect information, not counsel, help, or otherwise interact with the child. You also cannot protect them, or promise to protect them, in any way. Report the entire experience to the head researcher, who will make the appropriate follow up.

Emotional Responses

Denial- Denial is when someone chooses to ignore, disbelieve, or misreport the facts. Accept that some children may use this response as a coping mechanism.

Blame- People often look for others to blame about HIV and AIDs. Often infected children have reason to blame their parents for their infection, but it is very difficult for them to actually blame someone they love for having given them this terrible burden. Children may ask themselves who is responsible for their disease, or infecting their mother. Encourage the child to focus on the future instead of things that happened in the past and cannot be changed.

Guilt- Children may believe they have done something wrong to cause themselves to be HIV +. Also, because HIV is acquired sexually, they may be embarrassed and uncomfortable with the behavior that has caused the condition.

Anger- anger is a natural reaction when we are unhappy with a situation and wish it would change. It can be expressed outwardly or inwardly. Allow children to express feelings of anger freely. Orphaned children may turn the anger on themselves because they were unable to prevent their parent's death.

Fear and Shock- Fear is a survival instinct we use to cope with a threatening situation. Children are often very scared by the sickness or death of a parent or being sick themselves, and the uncertainty of their own future. Never imply that AIDS or death is a form of punishment from God, the spirits, or any person.

Shock is another coping mechanism we use to protect ourselves. It is often associated with numbness, confusion, or lack of connection to the world around us. For example, a child who has been told that he or she is HIV+ might behave as if nothing has changed.

Social Effects- The social effects experienced by children who are HIV+ or affected by HIV and AIDS are many and various. For example, a child whose parents or older siblings are sick may face increased responsibility, and experience a drop in school performance. A child who is HIV+ might act out rebellious behavior or experience rejection or rumor from friends and neighbors. In particular, children often experience **stigma- unyanyapaa**.

Stigma is a negative moral judgment that may arise from cultural, traditional, or religious beliefs and can be perpetuated by social isolation. For example, infected children might be teased with AIDS jokes in the playground, or have no one to play with. Or an orphaned child might be labeled an AIDS orphan, or become isolated from friends because the family can no longer afford to send him or her to school.

At all times remember why this research is important- We are working to ensure that Tanzanian children who are orphaned and HIV infected receive their rights as guaranteed by the African Charter and the UN Convention on the Rights of the Child. When we know what they need, we can work with stakeholders to develop responses that support these children and their integration into the greater society.

APPENDIX D

INTERVIEW GUIDE

Research Question	Interview Question or Protocol
How do these children rate on standardized quality of life indicators?	**1. How many people live in your home?** **2. Do you have a blanket?** **3. How far is the water from your home?** **4. How many times do you eat each day?** **What do you usually eat?** **5. Do you have a school uniform?** **6. Is there a bed net where you sleep?** **7. Do you have eating utensils that are just for you?** **8. Do you ever share a cup?** **9. Do you like to play sports and run around?** **10.What kinds of things do you like to do when you are playing outside?** **11. Do you sometimes have trouble sleeping?**
How do HIV-infected Tanzanian orphans think they compare to other children (A) physically, (B) intellectually, (C) emotionally, and (D) socially?	**1.How is it hard or different to be a kid who is sometimes sick rather than to be like other kids who aren't sick as much?** **<u>Possible Probes</u>** **1. What are the things you can do just as well as other kids who aren't sick so much?** **2. What do you tell others about taking medicine?** **3. Do you sometimes have to miss school because you are sick or need to go to the clinic?** **a. What is it like to miss school to go to the clinic?** **b. Who decides if you miss school because you are sick?** **2. Do you believe it is true or not true that you can control if you get sick, or how long it will take to get better? Is it luck?** **3.<u>Administer Pain Scale Instrument.</u>**

	4. I want to read you a story and have you tell me what you think about it. Read School Scenario 1. **Possible Probes** **Do you think any of these things?** **1. To help myself feel better, I think about other people who also get low grades and aren't helped by their teachers.** **2. Many students like me don't get good grades or help from their teachers, so it isn't important.** **3. I know I am smart so the bad grade really isn't a good measure of my abilities.** **4. The low grade and no help might be because the teacher knows I am HIV positive.** **5. Is it easy for you to make friends at school?** **Possible Probes** **1. Why or why not?** **2. In what ways are you the same and what ways are you different?** **3. If no, what do you do tell yourself to make yourself feel better?** **4. Is there anything you can do to encourage others to be your friend?** **5. Do other children ever avoid you or tell others to avoid you? Why do you think that is?**
How do HIV infected Tanzanian orphans perceive what the society is telling them about their identification as orphans infected with HIV?	**1. Draw a picture of the people who live in your home.** **Probe: Tell me about them.** **2.I am going to read you two stories about children like you. Orphan scenarios.** **a. Which story is more like your life? (for children living in non-institutional settings)**

	b. Which story is more common for children who do not live with their parents? (for children living in both institutional and institutional settings) **Possible Probe** **ado you think that orphans are treated differently than other children?** **b.How? Is this a problem?** **3. Sometimes people say that my hair looks funny, or make fun of my clothes. Has anyone ever called you a bad name or something like that? What did they do?** **4. Do people ever tell children like you that they are worthless and have no future? Why do you think they do that?**
What factors are present that support these children in coping with both orphanhood and positive HIV stat us?	**1.When you have a problem do you talk to others to help figure it out or try to solve it on your own?** **Possible Probes** **a. If you did decide to ask for help, who would you turn to?** **a. Would you pray?** **b. Do you think other people, or you yourself know what is best for you?** **2. If I said that most things happen just because of good or bad luck, would you agree with me or not? Why?** **Possible Probes** **ado you remember a time when you got what you wanted? What happened?** **3.What do you want your life to look like when you grow up?**

	Possible Probes **a. What would you need to do to make that happen?** **b.What else would need to happen?** **c.Who would help- caretakers, siblings, friends, teachers or church, luck, only you yourself? Others?** **4.Do you think it is best to accept a bad situation rather than trying to fix it?** **5.If someone at Holy Cross or in your community becomes very sick, or maybe dies, does it make you worry about yourself?** **6.When you are very hungry and there is nothing around to eat do you just try not to think about food?** **7.Read School Scenario 2. Who should decide what the student should do, the child or the teacher?** **Possible Probes** **a. Is it alright for a teacher to tell the child what to do?** **b.Does a child have to do everything a teacher tells them to do even if they don't want to? .** **c.Why should the child do/not do what the teacher says?** **c. What would be the best way for the teacher to solve the disagreement? (Choose: demand, punishment, negotiation, explanation)**
How do HIV infected Tanzanian orphans living in institutional settings compare on the above four parameters	**Data analysis will provide the basis for comparisons.**

to similarly described children living in village settings?	

School Scenario 1. You do homework for school that gets a bad grade. You need help and you ask your teacher for help, but they won't help you.

School Scenario 2. Grace/Alex is enjoying drawing a picture at school. Her(his) teacher says she(he) should go outside to play.

Orphan Scenario 1. Fatima is 11 years old. She is living in the home of her uncle and his wife who have 2 daughters who are older than she and one son who is younger. Every day before she can go to school she must carry water and cook breakfast for the family. After she returns home from school, she must tidy the house. This leaves very little time to rest, and if she complains that she is tired or feeling sick her uncle's wife will shout at her and tell her she is a burden to the family. Also, she has been told that she should be grateful to have a home since her parents have died.

Orphan Scenario 2. Ezekiel is 12 years old and lives with his guardian and her daughter. He has known the guardian for some years, as she was a friend of his mother before she died. Although there is not much in the home, Ezekiel receives as much food as the other child, and they share the work of the home equally. When Ezekiel is sometimes sick, his guardian takes him to the clinic or nurses him at home. The guardian is someone that Ezekiel can talk to about his problems, and who he feels really cares about him.

APPENDIX E

EXCERPT FROM RESEARCH LOG

2/21/09 Saturday- Orphanage First Interviews A-F

A	Female. Drawing house, then flower, then garden, then sky, then tree, then people. Took a long time before drawing people. Really liked the process- said these are questions she would ask of her own children when she has them.
B	Female. People only in picture- no dad. Made faces when asked about some of the drawing. Often nods rather than answering- took less than 30 minutes.
C	Male. Drew people very large, with their work accoutrements.
D	Male. Talked a lot about mother. They came from Kenya and she died here. Said Dad is in taxi business there but unreachable.
E	Male. “Only babies have mosquito nets here”. Intense concentration- tongue out when drawing.
F	Female. Very, very quiet.

NOTE: Look at colors chosen. Why they didn’t draw selves- only other people in the home.

BRACKET : Look at question asked- I expected a picture of 26 kids at orphanage- they drew people in “home place”.

NOTE: Think about the meaning of “babies” as used by E.

APPENDIX F

EXCERPT FROM A TRANSCRIPT

Excerpt from Transcript B-1

Elizabeth: Now -------, I shall read for you another short story of a girl child. She is called Grace. Grace enjoys to draw a picture being at school. Her teacher says she must go out to play. You have understood?

Child: Yes.

Elizabeth: Tell me now the story of Grace.

Child: Grace was there she was drawing a picture of teacher and she said this, go out to play, Grace said this- I don't want.

Elizabeth: Fellow, I have not said Grace said I don't want but she liked more to draw than to go outside. There you think who is responsible to decide it is what thing the pupil should do: Grace or Teacher?

Child: Grace.

Elizabeth: Why should it be Grace?

Child: Because Grace has manners.

Elizabeth: Do you think it is correct for teacher to tell a child what she should do? For example in the story I have told you, when teacher told Grace to stop to draw to play outside.

Child: It is not correct.

Elizabeth: Why is it not correct?

Child: He a teacher is not she the girl.

Elizabeth: And do you think that it is must that Grace should do everything teacher tells her even if she does not want to do?

Child: Yes.

Elizabeth: Even if she does not want?

Child: If she does not want, let her be beaten.

Elizabeth: Is that how you do it?

Child: Me, I read first then I go to play.

Elizabeth: But you listen to teacher what he tells you?

Child: Yes.

Child: Eehe.

Elizabeth: Why should Grace do everything that teacher says?

Child: Because teacher is big.

Elizabeth: If Grace wants to draw and teacher wants her to play out with her colleagues you think there is which good way for teacher to solve misunderstanding between him and Grace?

Child: Teacher should punish Grace-he should beat her.

APPENDIX G

EXCERPT FROM A DATA CHART

3B Stigmatizing Responses from Others (1 is Children, 2 is Adults)

A2	Sister James [teacher] "You, you people of _____ you are demons."
A1	Shares desk with another child- other kid said "move over- you have the AIDS. Don't sit close to me".
A2	"He does not come, you see those early morning they have a job of insulting you, big, big insults. [Why?] Because they know head teacher will not chase them. He does not chase him". [teacher]
A1	"It's the school pupils they bully me. Them, they hate me." [Why?] "I even don't know. I mean, even days when I play alone they just come they start to beat me". [Why?] "Me, I don't know".
A	"People look at me, you there, why don't you resemble with me? They come, they start to insult me."
B1	"Others run away from me!" [Why?] "Because, me, when I play with them they just run away from me." [You don't know reasons?] "No".
C1	[After going to clinic and missing school….] "Yesterday, you, why yesterday you have not come? Where were you? Maybe others if you go insult you". [How?] "Any that they will decide".
E	"I don't want them to know I drink medicines, absolutely. There are others you find they talk about you. They say, that child is sick. You see they stay far from me."
E2	"Teacher, you get teacher he discriminates you! You write well but he crossed you or you have got a question correct he crosses you."
F	"People do tell children like me [that they have no profit in their future days].
G2	[RE teacher not helping kid, asked do you think he knows something about the child so that is why he doesn't help?] "Me, I see teacher he knows absolutely that. That he has no parents".
G2	"That I am sick, I become different. I am told I am infecting others."
H1	"I mean they look at you like a rotten thing." [Males] "Eeh, others they tell you, they avoid you, others they don't avoid you." [Why] "I don't know".

APPENDIX H

CONFIRMATION OF PUBLIC DOMAIN INSTRUMENT

Subj: **Re: Pain Scale**
Date: 5/23/2008 12:03:48 PM Mountain Daylight Time
From: carl.vonbaeyer@usask.ca
To: CAROLSRP@aol.com

Thanks for your interest. I would be very interested in learning more about your study. The Faces Pain Scale - Revised (FPS-R) has been used in a number of developing countries, including Thailand, Jordan, Morocco, Brazil, and others, and eventually a review of this cross-cultural literature will be desirable. I had hoped at one point to study pain in child amputees in west Africa, but so far I haven't had time (i.e., courage has failed me).

Meanwhile, the FPS-R is available free for clinical and research use without any special permission. Please see **www.painsourcebook.ca** . The instructions are currently available in about 35 languages, including Malagasy but not yet including Swahili or any other Tanzanian languages. If you would like to provide translations into the language(s) you plan to use, guidance for the translation and back-translation process is on that website.

(If any commercial reproduction is planned such as reprinting the scale in a journal article, then permission should be sought from the copyright holder. Again, information is available on that website.)

I hope to hear from you again.

Carl

–

Carl L von Baeyer, PhD
Registered Psychologist
Professor of Psychology &
Associate Member in
Pediatrics
University of Saskatchewan

9 Campus Drive
Saskatoon, SK S7N 5A5 Canada
Fax +1 306 966 6630
carl.vonbaeyer@usask.ca
www.usask.ca/~vonbaeye/

–

On 5/23/2008 11:39 AM, CAROLSRP@aol.com wrote:

> Dear Dr Von Baeyer:
>
> I am working on my PdD dissertation on Tanzanian children who are HIV infected orphans and hoping to use elements of the Faces Pain Scale in my interview process.I would greatly appreciate your permission to do so. Full credit for the instrument will be provided in the document.
>
> Thanking you in advance,
>
> Carol Parker MPH
> University of Illinois at Chicago
> Walden University
> www.carolsrp@aol.com

CURRICULUM VITAE

EDUCATIONAL HISTORY

Doctor of Philosophy in Public Health November, 2009
Walden University Minneapolis, Minnesota

- Specialization in Health Promotion and Education
- Projects Concentration in Resource-Poor Environments
- Dissertation title: *The Lived Experience of HIV Positive Tanzanian Orphans*

Master of Public Health 1993
University of Illinois at Chicago
Specialization in Health Resource Planning and Management

Bachelor of Arts 1970
Ohio University Athens, Ohio
English Language and Literature

EMPLOYMENT HISTORY

Executive Director 2004-present
Pamoja Project Santa Fe, New Mexico
Non-profit organization providing collaborative planning and financial support for community-based HIV/AIDS programming with non-governmental organizations in Tanzania

- Created government-lauded Community Health Worker Network
- Designed micro-lending and psycho-social support programs for people living with HIV/AIDS
- Researched and implemented economic and educational support programs for orphans
- Increased annual donations from $15K to over $100K in 3 years

Volunteer 2000-2004
CASA (Court Appointed Special Advocate) Santa Fe, New Mexico

- Advocated for and appeared in court for neglected and abused children in state custody
- Wrote and taught *Money Smart*, a money management curriculum for guardians and parents seeking return of custody of their children
- Member of the strategic planning committee

Owner 1995-1999
Railyard Books General Book Store Santa Fe, New Mexico

Staff Specialist, Division of Strategic Planning and Marketing 1990-1993

Assistant Director, Society for Healthcare Planning and Marketing
American Hospital Association Chicago, Illinois

- Researched and wrote publications ranging from the annual Environmental Assessment to reports for constituent groups of physicians and other hospital-based professionals
- Refereed Foster McGaw Prize for Hospital Excellence in Community Outreach

Researcher and Manuscript Editor 1990-1991
University of Illinois at Chicago, Department of Public Health Chicago, Illinois

- Peer edited *The Disability Business* (1991), Gary L. Albrecht, Newbury Park: Sage.
- Performed qualitative data analysis on faculty research

PRESENTATIONS

International AIDS Conference, Mexico City 2008
A Community Health Worker Program Toolkit

State of New Mexico, Department of Health 2007
An Assessment of the New Mexico Behavioral Health Purchasing Collaborative

Conference on Social Change, Walden University 2006
HIV-Positive Orphans: Strategies for Care in Resource Poor Settings